Wired for Health and Well-Being
The Emergence of Interactive Health Communication

Science Panel on Interactive Communication and Health

Office of Disease Prevention and Health Promotion
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Foreword

As we close out the century, the promise of good health for all Americans seems both tantalizingly close and frustratingly far away. We have made great strides in preventing disease and extending life. However, the science base, which makes progress possible, has not been effectively shared among all who need to understand and act on it. We can do a better job of translating this knowledge into useful communication for all people, and extending it to underserved populations who often carry the heaviest health burdens. New and emerging communication tools may help bring life-enhancing knowledge to people in ways they can use, when and where they need it.

Information and education have long been vital tools for promoting health, controlling disease, and raising the quality-of-life in our families and communities. The desire to improve the health status of all Americans, while ensuring that those facing the highest risks receive special attention, is prompting, among other efforts, innovative communication activities to improve health-related decisions by the public and health professionals and to strengthen the relationships between them. Increasingly, these health communication activities incorporate computer-based programs, including health-related Web sites, online discussion groups, and e-mail. The rapid development of new technologies, coupled with the explosive growth of the Internet, brings opportunities for people to find interactive information, education, and support that is tailored to their needs and preferences. Equally important, the new connectivity creates links among individuals, public agencies, businesses and employers, community resources, health professionals, health plans, academic institutions, and other private organizations—all of which, together, are necessary to ensure health and well-being.

To date, there has been little evaluation or quality control of interactive health communication because applications have been developed faster than theory and assessment tools. The Science Panel on Interactive Communication and Health has carefully considered the issues involved and defined the problems and opportunities. Their path-breaking work presents a broad strategy and specific guidance for promoting sound, appropriate assessment of this emerging field. This report will be valuable for all those who are interested in ensuring the quality and effectiveness of these exciting, but often misrepresented, health communication innovations. Each stakeholder, including policymakers, health care providers and purchasers, public health professionals, application developers, and consumers and patients, has a special role to play. Together, we can ensure that information and communication technologies fulfill their promise and contribute to better health and well-being for all people.

David Satcher, MD, PhD
Assistant Secretary for Health and
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Preface

This is the report of the Science Panel on Interactive Communication and Health (the Panel) on the emerging field of interactive health communication (IHC). It is intended primarily for developers and users of applications, researchers, clinicians, public health professionals, and policymakers from both the public and private sectors. This report provides information and analyses about this field so that IHC stakeholders may be better able to make critical decisions about IHC—its development, use, purchase, evaluation, and policy environment.

The Panel aimed for a report that is educational but not overly technical, provocative but not overly speculative, and grounded in science but cognizant of "real-world" considerations. Because of the growing breadth and depth of IHC, the Panel was unable to address all the issues related to IHC within the confines of this document. Therefore, this report should not be considered a comprehensive review of the published literature in this field, and readers are encouraged to seek additional sources of information, such as the resources cited in this report. Because of the rapid advances in information and communication technology and its evolving impact on health care and public health, the Panel was challenged to produce a report that would not be quickly outdated. New technologies for facilitating health communication will undoubtedly be utilized as they become available. However, the Panel anticipates that the central theme of this report—the need to focus on an evidence-based approach to IHC—will be relevant for many years to come regardless of the communication technologies and media employed.

In this report, the Panel concludes that, as with other complex health issues, a multifaceted approach is necessary to ensure that the potential of IHC to improve health is fully realized. The Panel's recommendations pertain to many different stakeholders who comprise "the field" of IHC. The Panel hopes that its analyses and recommendations will help catalyze further discussions, initiatives, and partnerships around IHC that lead to a healthy future for all.

David H. Gustafson (Chair)
Thomas R. Eng (Study Director)

Acknowledgments

This report and the project from which it was generated represent the collective interests and efforts of many people to whom the Panel extends its gratitude.

The project was originally conceived by Mary Jo Deering in the Office of Disease Prevention and Health Promotion (ODPHP) at a time when many people did not yet recognize the potential impact of information and communication technology on health. It was primarily her vision, enthusiasm, and leadership that made this project possible. The project's successful launch was ensured by Kevin Patrick, while serving as Senior Technology Advisor in ODPHP, Steve Downs, while serving as ODPHP Technology Advisor, and Catherine Crawford, while in the Office of the Assistant Secretary for Planning and Evaluation. Michael McGinnis, Earl Fox, Susanne Stoiber, and Linda Meyers, ODPHP directors at the time of this project, provided critical support for this effort.

The following people contributed to the development of this report: Paul Kim (research); Mary Jo Deering and Andrew Maxfield (drafts of materials); Dawn-Michele Gould, Linda Friedman (copyediting); David Peabody, Janice Radak (layout, graphics, design, and production); and Rosie Dempsey (report dissemination). The numerous Panel meetings and conference calls would not have been possible without the logistical support provided by Cecile Douglas and Sandy Saunders. The assistance of Kristine McCoy to the Panel's early efforts is greatly appreciated.

The Panel is particularly grateful to Anne Restino for spearheading the design and development of the Panel's Web site (www.scipich.org). Paul Kim, Andrew Maxfield, Stacey Berry, Arlene Weitzman, and John Studach also contributed to development of the Web site.

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Executive Summary

The rapid proliferation of information and communication technologies that have emerged during the last several years has both hopeful and alarming implications for the future. These technologies have already produced profound changes in the US economy and continue to exert increasing influence on many aspects of daily life, including personal health decisions and behaviors, health care delivery and financing, and public health systems.

Evidence of this phenomenon is the growth of interactive health communication (IHC): the interaction of an individual—consumer, patient, caregiver, or professional—with or through an electronic device or communication technology to access or transmit health information, or to receive or provide guidance and support on a health-related issue. IHC applications include health information and support Web sites and other technology-mediated applications that relay information, enable informed decisionmaking, promote healthy behaviors, promote information exchange and support, promote self-care, or manage demand for health services.

The rapid evolution of IHC raises many questions about its impact on public health and health care and our ability to evaluate it. To help clarify these issues, the Office of Disease Prevention and Health Promotion of the US Department of Health and Human Services convened the Science Panel on Interactive Communication and Health (the Panel), a 14-member, non-Federal panel of experts in many aspects of health and technology. This report summarizes the potential risks and benefits of IHC, the underlying science or evidence base for IHC, mechanisms for improving IHC quality and effectiveness, appropriate roles and responsibilities for IHC stakeholders, and relevant major policy and research issues. The report also presents the Panel's consensus recommendations about national initiatives that are needed to achieve a preferred future for IHC.

IHC applications have great potential to improve health and well-being. Compared to more traditional media, interactive media may have several advantages for health communication efforts. These include: improved access to individualized health information; broader choices for users; potential improved anonymity of users; greater access to health information and support on demand; greater ability to promote interaction and social support among users, and between consumers and health professionals; and enhanced ability to provide widespread dissemination and immediate updating of content or functions.

IHC applications also may cause harm. A growing variety of entities and individuals—many of whom lack adequate expertise and training in the health and communication sciences—are developing, sponsoring, and disseminating IHC applications. The proliferation of applications available to the general public, who may not have the skills or background to evaluate the quality or relevance of applications, raises concerns about their potential to cause harm, their impact on health care quality and cost, the clinician-patient relationship, and the organization of medical systems. Without appropriate attention to these and other issues, IHC applications may result in inappropriate treatment, delays in care, damage to patient-provider relationships, violations of privacy and confidentiality, wasted resources, delayed innovation, unintended errors, and an increased technology and health gap.

To date, few IHC applications have been adequately evaluated for quality or effectiveness. Some health communication interventions have been shown to be efficacious, but research on the effectiveness of computer-based approaches is limited. Potential benefits of evaluation include improved quality, utility, and effectiveness of applications; reduction of likelihood of harm; better use of resources for effective applications; greater participation of stakeholders in the application development and implementation; and improved decisions about use of applications. The Panel has developed an “evaluation reporting template” and a “disclosure statement” to promote evaluation and assist developers in disclosing essential information about their applications to potential purchasers and users.

The Panel has identified several stakeholder groups that need to participate in IHC application development, evaluation, and quality assurance activities if meaningful evolution and quality improvement of IHC is to occur. These include consumers (e.g., patients, families, and caregivers), application developers, purchasers, health professionals, and policymakers, all of whom have related roles and responsibilities. Understanding the concerns, motivations, and perspectives of each stakeholder may be valuable in establishing collaborative efforts and in arriving at a consensus on appropriate directions and policy for IHC.

Currently, most health information policy discussions at the national level are centered largely around issues related to health care, provider-focused systems rather than consumer-focused applications. Major policy issues that are relevant to the development, implementation, and evaluation of IHC applications include standards, privacy and confidentiality, oversight and regulation, liability, accreditation and certification, public investment in development and research, payment and reimbursement, integration of IHC with health care and public health, and access to IHC.

The Panel developed the following vision for IHC:

> *"Interactive health communication will play an essential role in enhancing health, minimizing total burden of illness, and optimizing relationships between individuals and health professionals."*

The Panel proposes four overarching strategies to achieve this vision: 1) strengthen evaluation and quality of IHC, 2) improve basic knowledge and understanding of IHC, 3) enhance capacity of stakeholders to develop and use IHC, and 4) improve access to IHC for all populations. The Panel considers widespread evaluation of applications and dissemination of evaluation results to be the primary mechanisms to improve quality of IHC and to ensure positive outcomes. Because of the newness of the field, scientific knowledge about many aspects of IHC is very limited. Greater knowledge is needed to improve the effectiveness of IHC, inform application design and implementation, and, ultimately, further appropriate public policy. The Panel also identified major gaps in resources available to application developers and shortcomings in the skills of users. These deficiencies will need to be addressed to ensure the continued development of innovative applications and the ability of intended users to take full advantage of IHC. Finally, enhancing access to IHC for all populations is essential because, without equitable access, evaluation efforts will be incomplete and the potential for IHC to provide benefits to entire communities is not likely to be realized. Specific recommendations under each major strategy follow.

STRATEGY 1. STRENGTHEN EVALUATION AND QUALITY OF IHC

- Purchasers of IHC applications should require developers to integrate evaluation methods into product development and implementation as a condition of purchase.
- Developers should publicly disclose information about their IHC

application including identity of developers and sponsors, purpose of the application, source(s) of content (including disclosure of advertising), privacy protections, whether and how the application was evaluated, and the results of evaluations.

- Developers of IHC applications should adopt voluntary quality standards for application development.
- As a primary criterion for their review and rating of IHC applications, individuals and organizations that conduct reviews of applications should include information on whether and how the application was evaluated for effectiveness.

STRATEGY 2. IMPROVE BASIC KNOWLEDGE AND UNDERSTANDING OF IHC

- Public and private sector organizations with an interest in health and technology should establish a formal process for identifying and addressing current knowledge gaps and priority areas for basic and applied research, application development, and demonstration projects.
- A cross-governmental and interagency initiative to coordinate Federal and State funding in the area of IHC should be established.
- A long-term initiative to monitor and assess the health, economic, and social impact of IHC should be established.
- Programs to monitor and analyze trends in IHC policy development should be established for the purpose of improving policy.
- Entities responsible for assuring the quality of personal health services, in conjunction with appropriate government agencies, should determine where responsibility and authority rests for ensuring the privacy, confidentiality, and security of IHC-related information.

STRATEGY 3. ENHANCE CAPACITY OF STAKEHOLDERS TO DEVELOP AND USE IHC

- A clearinghouse for public domain objects and tools, raw materials, and information resources for IHC applications should be established for public use.
- Government agencies, foundations, and investors should strongly encourage IHC developers to explore academic-industry collaborations and other partnerships that enhance application quality and evaluation by funding developers who propose these activities.

- Programs to monitor and improve public literacy in health and technology should be supported by government agencies, private foundations, corporations, and nonprofit organizations.
- Health professional schools should include IHC in core curricula to promote its integration into clinical practice.
- Performance indicators that monitor health plan efforts to help members and patients locate and critically assess health information and support resources should be developed and implemented.
- Process and organizational models for effective implementation of IHC applications should be developed and evaluated.
- Financial models should be developed and tested to determine whether they support appropriate use of effective IHC applications.

STRATEGY 4. IMPROVE ACCESS TO IHC FOR ALL POPULATIONS

- Entities with an interest in health and technology should promote public and professional education about the availability, selection, and optimal use of high-quality IHC applications.
- Public-private initiatives to enhance access to IHC among the underserved should be established.
- Mechanisms and models should be established to fund the development and implementation of orphan applications, including applications for underserved populations.

There is little doubt that IHC applications will continue to grow in utility and popularity and consumers will increasingly turn to them for health information, communication, support, and health-related transactions. IHC has the potential to dramatically improve the ways in which people prevent disease, maintain their health, and recover from illness. However, for IHC to play a pivotal and positive role in creating a healthier society, a broad range of stakeholders must participate in application development and evaluation. An evidence-based approach to the development and diffusion of IHC applications is central to the process of ensuring that such applications are of high quality, effective, and accessible to all.

I

Introduction

Virtually all aspects of society have been altered in some way by recent advances in information and communication technologies. In 1997, the information technology industry was the single largest industry in the United States in terms of sales and accounted for 33 percent of the growth in the gross domestic product in 1996 (AEA, 1998; NTIA, 1998). The percentage of US households with personal computers grew from about 8 percent in 1984 to 45 percent in 1998 (US Bureau of Census, 1998; ZD Market Intelligence, 1998). From its roots in the scientific and engineering community, the Internet has grown to become a central focus for commerce and communication—so large that even the best search engines can only catalog about 28 percent of the information on the World Wide Web (Lawrence and Giles, 1998). In mid-1998, more than 70 million US adults were active users of the Internet (NMR, 1998; Wiese, 1998) and the number of users worldwide is increasing exponentially for the foreseeable future. About one-half of all US Internet users have used it to obtain health information or support (FIND/SVP, 1997). Advances in technology have catalyzed dramatic changes in many aspects of the economy and society including commerce, financial services, telecommunication, and delivery of news and information. Other information-intensive sectors, such as health care and public health, are in the early stages of change.

Concomitant with the emergence of new media technologies, consumers are becoming increasingly assertive in health care decisionmaking and in demanding increased access to a wider range of health information and social support resources. For example, less than one year after free Medline searches became available on the World Wide Web, the number of searches increased tenfold, and 30 percent of users were members of the general public (NLM, 1998). In addition, the growing number of persons enrolled in managed care organizations in the United States—from 36.5 million in 1990 to about 67.5 million in 1996—has long-term implications for the delivery of health services and demand for health information (AAHP, 1998). At the interface of these trends, the interactive communication technologies have emerged to address the health information and support needs of consumers. Stakeholders involved with the development, dissemination, and evaluation of these technologies are now in need of input and guidance to ensure quality of, and achieve an optimal future for, these technologies (Thomas, 1996; Sonnenberg, 1997; Robinson et al., 1998).

Interactive health communication (IHC) can be defined as the interaction of an individual—consumer, patient, caregiver, or professional—with or through an electronic device or communication technology to access or transmit health information, or to receive or provide guidance and support on a health-related issue (Robinson et al., 1998). The term "IHC applications" is used to refer to the software programs or modules that interface with users rather than the hardware and infrastructure technologies that run these applications. For the purposes of this report, IHC applications do not include electronic applications that exclusively focus on administrative, financial, or clinical data, such as electronic medical records, dedicated telemedicine applications, expert clinical decision-support systems for physicians, or applications focused solely on health professional education. Although most IHC applications involve the use of computers, the telephone, interactive television, personal digital assistants, and other communication devices are also employed.

The emergence of the field of IHC raises several major issues about its status, its future, and its ultimate impact on public health and health care. These include:

- The potential risks and benefits of IHC
- The science or evidence base for IHC
- Quality and effectiveness of IHC applications
- Appropriate roles for stakeholders in IHC development, implementation, and evaluation
- IHC-related policies and research
- Appropriate national initiatives to achieve a preferred future for IHC

To help clarify the above issues, the Office of Disease Prevention and Health Promotion (ODPHP) of the US Department of Health and Human Services (HHS) convened the Science Panel on Interactive Communication and Health (the Panel), a 14-member non-Federal panel. The Panel consists of nationally recognized experts in a range of study areas, including clinical medicine and nursing, public health, media and instructional design, health systems engineering, decision sciences, computer and communication technologies, and health communication.

The contents of this report represent the analyses and recommendations of the Panel, which were derived through a group consensus process. The Panel considered findings of published studies, online resources, and opinions of outside experts in formulating its recommendations. The Panel met 10 times over the course of more than 2 ½ years (May 1996 to February 1999). During this period, the Panel's work and drafts were reviewed and commented on by numerous "liaisons" to the Panel. These liaisons represented more than 50 Federal agencies and offices and non-Federal or private sector organizations, including government agencies, academic institutions, health care organizations, developers of IHC applications, health care consumers, and consumer advocates (see Acknowledgments). The preliminary work of the Panel also was presented at several national conferences on technology and health to obtain public feedback.

This report provides an analysis of the major issues related to quality improvement and evaluation of IHC applications, and suggests directions for future activities and policy in this area. The Panel initially focused its deliberations on issues related to quality improvement and evaluation of IHC, but it became clear that the related issues of public awareness and understanding of IHC, stakeholder capacity to develop and use IHC, and access to IHC also needed to be addressed in this report. Although IHC applications are being developed and used throughout the world, and emerging technologies clearly have transnational and global implications for health, this report focuses on the field of IHC as it is evolving in the United States. Additional analyses of this field in other countries are needed.

Although policymakers, developers and purchasers of IHC applications, and health professionals are the primary audiences of this report, consumers and others also may benefit from reading it. This report summarizes and organizes much of the Panel's previously published articles in scientific journals (Robinson et al., 1998; Eng et al., 1999; Gustafson, Robinson et al., 1999; Henderson et al., 1999; Jimison et al., 1999; Patrick et al., 1999) within a comprehensive framework for IHC. This framework serves as the basis for the Panel's recommendations for moving the field of IHC forward.

II

Interactive Health Communication

The variety and sophistication of IHC applications have increased dramatically during the last decade as a result of advances in multimedia technology and new communication channels such as the Internet. Indeed, the substantial increase in the number and sophistication of applications available on the World Wide Web just during the period that this Panel has met is a prime example of the dynamic nature of these technologies.

IHC applications are available on a wide variety of health topics and can focus on a single health condition or target a group of conditions. These programs range from applications designed to convey limited health information to complex clinical decision-support tools and modules that are designed to influence health behaviors. The degree of user interactivity can be limited and short-term (e.g., selecting an option to obtain specific health information) or involve a series of complicated interactions over a prolonged period of time (e.g., monitoring and managing a chronic health condition, shared decisionmaking applications). Applications can be developed using one medium (text) or multimedia techniques (combination of text, sound, and still graphics and video). In addition, systems-development costs can range from minimal costs to millions of dollars depending on complexity (GAO, 1996). There are also a plethora of vehicles and media for disseminating IHC applications. These include stand-alone or locally networked computers, the Internet (accessed through computers, kiosks, TV, or other electronic devices), dial-in services, cable, satellite and other wireless modes, and CD-ROM and DVD and other information storage and delivery technologies.

Whereas most health communication materials and programs were developed and sponsored primarily by government agencies and nonprofit health-related organizations in the past, there are now a growing variety of entities and individuals that are developing, sponsoring, disseminating, and using IHC applications. These include: individuals, families, and communities; information technology corporations (e.g., hardware, software, Internet, telecommunication, and mass media companies); employers and other purchasers of health services; the health care industry (e.g., managed care organizations and other health plans, pharmaceutical and other health care product companies); government agencies and public policymakers; health care professionals and professional societies; academic health centers and institutions; biomedical researchers; private nonprofit health-related organizations; schools; publishers; venture capitalists and investors; and commercial advertisers. A growing number of Internet companies, many of which have substantial financial backing from large corporations, have been specifically created to develop and market applications including "e-commerce" companies that sell health-related products and health "portals" that seek to attract users searching for health information and support (Fitzgibbons and Lee, 1999). A substantial number of developers, however, are nonprofit entities. Volunteers often run online peer support groups, one of the most commonly used IHC applications.

The background and training of developers in the health and communication sciences vary widely. Some developers may employ a large team of professionals with extensive experience and training in appropriate areas; other developers may be individuals without such credentials. Although many stakeholders are involved in application development, applications produced by large technology corporations and start-up companies, the health care industry, well-known private nonprofit health-related organizations, academic institutions, and government agencies are most likely to reach the largest number of users. Because of the global reach of many Internet-based applications, programs developed in one country may have implications for other nations. In addition, as application development tools become easier to use and the Internet becomes more pervasive, the number of individuals who develop health-related applications may increase. Currently, data about the frequency to which IHC applications are evaluated for effectiveness are not available; however, anecdotal information suggests that such evaluations are uncommon.

Functions of IHC Applications

IHC applications use technology to further the general goals of health communication—inform, influence, and motivate individuals, populations, or organizations on health-related issues (NCI, 1989). Although many applications focus exclusively on one function, an increasing number of applications encompass multiple functions. The range of specific functions of IHC applications include the following:

1. *Relay information.* These are applications that provide general or individualized health information on demand. Examples include Web sites, online services, and telephone-based applications that use interactive voice response and fax-back technology (Buhle et al., 1994; Wingerson et al., 1997).
2. *Enable informed decisionmaking.* These applications facilitate the health decisionmaking process of individuals and/or communication between health care providers and individuals (including consumers, patients, family members, caregivers, and others) regarding the prevention, diagnosis, or management of a health condition (OTA, 1995; AHCPR, 1997). Some applications assist individuals with health care decisions, such as selecting a health care professional, health plan, or nursing home (Meyer, 1996; Firshein, 1997). More sophisticated applications assist individuals in evaluating and selecting options that are consistent with desired health outcomes (Barry et al., 1995; Wennberg, 1995; AHCPR, 1997; Gustafson, Hawkins et al., 1999).
3. *Promote healthy behaviors.* These applications promote the adoption and maintenance of positive health behaviors on both an individual and community level. Some applications promote healthy habits by providing wellness information and explaining associated benefits and costs. Applications also include risk-assessment and health promotion modules typically based on theories of behavior change (Robinson, 1989; Skinner et al., 1993; Campbell et al., 1994; Strecher et al., 1994; Krishna et al., 1997).
4. *Promote peer information exchange and emotional support.* These applications represent some of the most common health-related uses of the Internet (Ferguson, 1996; Scolamiero, 1997) and enable individuals with specific health conditions, needs, or perspectives to communicate with each other, share information, and provide and receive peer and emotional support (Gustafson et al., 1992; Gleason, 1995; Bluming and Mittelman, 1996; Feenberg et al., 1996; Weinberg et al., 1996; Fernsler and Manchester, 1997; Peters and Sikorski, 1997). Online support groups exist for almost any health condition or health-related need (White and Madara, 1998). Participants in such support networks include consumers, patients, health professionals, and family caregivers (Brennan et al., 1995; Ferguson, 1996).
5. *Promote self-care.* These applications may either help users manage health problems without direct intervention from a health care professional or supplement existing health services by facilitating

remote health monitoring and care (Robinson, 1989; Ferguson, 1997; Shah et al., 1998). Some users may have limited access to a health care professional or seek information on therapies that may not be available from their health care provider.

6. *Manage demand for health services.* These applications provide specific information, tools, and other resources to support wellness, self-care, and self-efficacy, to enhance utilization of effective health care services and reduce use of unnecessary services (Robinson, 1989; Fries et al., 1993; Vickery, 1995). They are increasingly being used by health plans and employers to manage health care costs (Mullich, 1997). Examples include computer-assisted telephone advice systems, interactive voice response systems, clinician-patient e-mail, and other electronic consultations with health professionals (Balas et al., 1997; Kane and Zands, 1998).

The above functions also may extend the reach of clinical practice and enhance productivity by increasing patient access to clinician-approved health information without additional office visits. A continuum of clinician-patient contact may be established ranging from face-to-face visits to autonomous information delivery and/or exchange. In addition, reducing unnecessary or trivial visits may increase clinician satisfaction (Mechanic, 1970) and reduce health care costs.

It is likely that consumers will increasingly use the Internet and other networked technologies to conduct health care-related transactions to schedule appointments, fill prescriptions, enroll in health plans, choose providers, and purchase health-related products. Some health plans are already providing such access to improve efficiency and service. These functions are outside of the Panel's definition of IHC, but they may be bundled or integrated with the IHC functions described above.

Factors That Impact the Adoption of IHC

Many environmental factors may influence the adoption and use of IHC applications. Understanding the role these factors play in promoting or hindering adoption and implementation of IHC is critical to the identification of strategies that promote use of quality applications. Factors that promote adoption of IHC include:

1. *Increasing telecommunication and computing capacity.* The exponential increase in telecommunication and computing capacity during the 1990s in terms of data transmission speed, bandwidth capacity, computer processing power and software design, information storage capability, and transmission options (e.g., phone line, cable, wireless) have greatly spurred the development of IHC applications. Advances in software

authoring tools and increasing knowledge about how to design more intuitive IHC applications also have played an important role. Without these recent technological advances—in tandem with decreasing costs—it would be virtually impossible to deliver multimedia applications in an effective manner. In particular, the rise of global communication networks, such as the Internet, has presented an enormous opportunity to distribute such applications widely and inexpensively, and link and build upon multiple applications.

2. *Increasing computer literacy and access.* The exponential increase in computer literacy and public access to personal computers and the Internet are major factors for the increasing popularity of IHC applications. Computer literacy among Americans will continue to rise as increasing numbers of people have access to computers at work, at home, or in public access points.

3. *Increasing consumer demand for health information and shared decisionmaking.* Consumer demand for health information is substantial and increasing (GAO, 1996). For example, telephone inquiries to the HHS-sponsored clearinghouses increased an average of 209 percent from 1990 through 1994 (McGinnis et al., 1995). Surveys show that most Americans place a high value on access to health information (Deering, 1996), and that searching for health information is one of the most popular reasons for using the Internet (FIND/SVP, 1997). The nature of public inquiries to government-sponsored information clearinghouses seems to have shifted from primarily questions about general wellness and healthy lifestyles in the 1980s to requests for information on diagnosis and treatment of specific diseases and health conditions in the 1990s (McGinnis et al., 1995). Major reasons for the increased demand for health information and shared decisionmaking (HCI, 1994) include: 1) growing recognition of the complexity of medical decisions and that health choices may depend as much or more on patient preferences as on medical science;[1] 2) increasing concern about the effect of financial incentives on clinical decisions and increasing distrust of health care institutions, which may lead people to seek independent information and second opinions; 3) rising interest in “self-care” where people seek to prevent, diagnose, and treat health problems with no or limited intervention from traditional health care professionals; 4) the “aging of America,” which has resulted in a growing number of persons with chronic health conditions and/or their caregivers—both of whom have substantial health information and support needs; 5) growing interest in alternative approaches to

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[1] Shared decisionmaking is the process in which health care professionals and patients (or other interested parties) jointly assess and decide on treatment options.

established health care remedies (Eisenberg et al., 1998); and 6) increasing investment of the pharmaceutical and other health care companies in direct-to-consumer communication about medications and other health interventions (Jupiter Communications, 1998).

4. *Increasing emphasis on primary and secondary prevention.* Because many health conditions do not have effective therapies, clinicians and health officials are recognizing the pivotal role of primary prevention (USPSTF, 1996). IHC applications can be used in prevention programs to promote healthy lifestyles, encourage positive behavior change, and facilitate delivery of preventive health services. There also is an increasing emphasis on prevention-related quality indicators [e.g., the Health Plan Employer Data and Information Set (HEDIS) of the National Committee for Quality Assurance]. IHC may be a mechanism to move these forward.
5. *Increasing trend to reduce cost of health care services.* The national trend towards managed care reflects efforts to improve the coordination of health services and to reduce the cost of health care. A recent study estimates that US health care expenditures will almost double from $1.1 trillion in 1998 to $2.1 trillion in 2007 (Smith et al., 1998). Some health plans, including managed care organizations, may be likely to implement preventive health applications because they have the infrastructure to employ these technologies. Some have a strong focus on preventive health and a financial incentive to use potentially cost-saving technologies.

Barriers to the widespread adoption of IHC include:

1. *Health care provider resistance.* Some health care professionals may not be supportive of IHC applications because use of this technology may be perceived as a threat to professional autonomy and authority. With increasing access to specialized health information and expert knowledge systems, health professionals may be perceived as only one of many legitimate sources of information. Some believe that cost-conscious managers may use IHC applications to supplant rather than complement clinician interactions with patients. In addition, some providers are concerned about potential, professional liability issues associated with adopting IHC applications.
2. *Lack of financial incentives to change behavior.* The lack of financial incentives for health care providers to support or adopt IHC applications adds to provider resistance. Without reimbursement for IHC-related services from health plans and other payers, it is difficult to motivate behavior change. In addition, existing capital investments by some health organizations in information systems and applications that do not support or integrate well with new applications are substantial

disincentives to implementing new programs.

3. *Lack of access to infrastructure and inability to utilize applications.* Residents of rural areas, inner cities, and lower socioeconomic status neighborhoods tend to have less access to computer and communications infrastructure than persons in other areas (US Department of Commerce, 1995). Widespread adoption of IHC applications will be impeded as long as a substantial proportion of the population, including low-income, rural, and inner-city families; certain racial/ethnic groups; disabled persons; and the elderly, lack access to technology infrastructure or lack the ability to utilize applications because of illiteracy, language, and other factors (Eng et al., 1998).
4. *Substantial implementation and maintenance costs.* Implementation and maintenance costs associated with some IHC applications may be substantial in terms of investing in necessary software and hardware, training of program implementation and maintenance personnel, and support costs. IHC applications with sophisticated multimedia features, for example, may require updated computer equipment or large bandwidth capacity to run efficiently, thus requiring substantial capital to acquire or update equipment. This may be prohibitive to smaller corporations or health plans. There is also a lack of understanding of how to implement and maintain IHC applications within the context of the structure, policies, and procedures of health care institutions or larger health care systems.
5. *Lack of convincing data on effectiveness.* A number of studies have demonstrated a positive impact in providing the kind of information often included in IHC applications, but more data are needed to persuade skeptical decisionmakers in health plans and provider organizations. Self-care books provided to members of health maintenance organizations and to Medicare beneficiaries have been shown to reduce office visits and specialty referrals (Vickery et al., 1988). Interventions designed to help patients prepare for office visits have been shown to improve treatment outcomes for chronic diseases (Greenfield and Kaplan, 1985). In addition, computer access to support groups and decision guidance has been shown to positively impact on women with breast cancer and patients with AIDS (Gustafson et al., 1993, 1994; McTavish et al., 1994). Shared decisionmaking programs have been shown to improve health outcomes while reducing the utilization of surgery and other high-cost interventions (Barry et al., 1995; Morgan et al., 1997). For IHC to be widely adopted, additional data are needed in such areas as effectiveness and cost-effectiveness in specific populations and health care settings.

Benefits and Risks of IHC

Interactive media are changing the design and delivery of health communication. Some health communication interventions using traditional media, such as radio, television, and printed text and pictures, have been effective in improving knowledge and promoting healthy behaviors (Flay, 1987; Flora et al., 1995), but emerging media may have several advantages for health communication efforts. These include:

1. *Improved access to individualized health information.* The interactive nature of emerging technologies allow the "tailoring" of information or support to the specific needs or characteristics of individuals or groups of users (Harris, 1995).
2. *Broader choices for users.* The ability to selectively combine text, audio, and visuals enables designers to employ specific media based on the purpose of the intervention and the learning styles of users (Harris, 1995). The ability to easily create multiple versions of an application means that users have a wider spectrum of products from which to choose.
3. *Potential improved anonymity of users.* These technologies, when used appropriately, can help protect the anonymity and privacy of people who access sensitive information by bypassing the need for people to obtain such information in public or face-to-face settings (GAO, 1996). Computer-based interfaces also can improve the quality of personal health information, such as health status, health risks, and fears and uncertainties, collected from individuals (Locke et al., 1992; Gustafson et al., 1993). This allows health professionals to better assess and manage those in need.
4. *Greater access to health information and support on demand.* These resources often can be used at any time and from numerous locations through the Internet (Harris, 1995; GAO, 1996).
5. *Greater ability to promote interaction and social support among users and between consumers and health professionals.* Through the use of networking technologies, such as e-mail and synchronous communication, barriers to direct communication among peers and between consumers and health professionals are reduced (Robinson et al., 1989; Harris, 1995; GAO, 1996; Pingree et al., 1996).
6. *Enhanced ability to provide widespread dissemination and immediate updating of content or functions.* Provided that technology infrastructure is established, applications can be rapidly distributed to many audiences at relatively minimal cost (GAO, 1996).

In addition, emerging technologies such as the Internet, allow users to also become developers and active participants in the information exchange process—they can glean what they wish from various sources and create and disseminate new information. Thus, these users become health communicators.

Although the potential benefits of IHC are impressive, there is the risk of harm. The proliferation of IHC applications that are available to the public raises legitimate concerns about their potential to cause harm especially among those who may not have the skills or background to evaluate the quality or relevance of IHC applications (Consumers Union, 1997; Silberg et al., 1997; The Lancet, 1997). Public use also may impact health care quality and cost, the clinician-patient relationship, and the organization of health care systems (HCI, 1994; Kassirer, 1995; Blumenthal, 1997). There has been minimal research about the potential risks associated with the widespread use of IHC, and documented cases of harm are relatively rare (Weisbord et al., 1997). Use of inappropriate or poor quality applications, however, can result in the following potential negative outcomes:

1. *Inappropriate treatment or delays in care.* Inaccurate or inappropriate health information and support could result in inappropriate treatment or cause delays in seeking appropriate health care (Goldwein and Benjamin, 1995; Saksena and Nickelson, 1995; Keoun, 1996b; FDA, 1997; Impicciatore et al., 1997; Scolnick, 1997; Weisbord et al., 1997). For example, misleading claims for medical products and health care fraud are endemic on the Internet (FTC, 1997), and, in at least one documented instance, resulted in use of a harmful product (Weisbord et al., 1997). People may be particularly susceptible to questionable marketing practices when they have a serious illness and are desperate for potential cures. Another possible source of inaccurate or inappropriate information is online support groups, where such information may spread rapidly before being corrected, or where the experiences of one or a few individuals are inappropriately applied to others who share the condition but may differ in other important characteristics (Bulkeley, 1995; Gray, 1998).
2. *Damage to the patient-provider relationship.* Inappropriate use of IHC applications can result in people losing trust in their regular health care providers and prescribed treatments and lead them to seek inappropriate care or care from questionable providers. Use of inappropriate applications can also lead to unnecessary conflicts and confrontations between consumers and health care providers (Bero and Jadad, 1997).
3. *Violations of privacy and confidentiality.* As the ability of IHC applications to tailor health information and support becomes increasingly utilized, more potentially sensitive personal data will be collected through applications based in workplaces, health care

organizations, and public networks. Without adequate safeguards, such data and information may be shared or sold to others without the user's knowledge or permission, or used for unintended or illegal purposes.

4. *Wasted resources and delayed innovation.* Unless adequate information about effectiveness and cost-effectiveness of specific IHC applications is available, ineffective or inefficient applications may be adopted leading to wasted resources and delayed innovation. As noted previously, relatively few applications have undergone scrutiny to ensure that they produce their intended effects. Lack of understanding of user needs also may contribute to development of inappropriate resources.
5. *Unintended errors.* As new software tools, such as "agents" (discussed later in this chapter), become available, developers will use them to create increasingly complicated programs that may employ complex algorithms transparent to the user. Many of these applications will be developed by multiple individuals who may not be aware of potential adverse interactions between application components. This may lead to instances where complex IHC applications, such as shared decision support programs, produce unintended errors that result in harm.
6. *Widening the technology and health gap.* As IHC applications become more pervasive and the Internet and other technologies become essential components for delivery of health information and care, those without access to these technologies may fall further behind in their ability to obtain information and care (Eng et al., 1998; Hoffman and Novak, 1998; US Department of Commerce, 1998). There are currently few initiatives that provide access to technology to underserved populations, such as low-income populations, residents in rural areas, and those with disabilities.

Many of the concerns cited also apply to more traditional communication media. The Panel believes that the emphasis on the potential for harm from IHC applications, however, is justified because new and emerging media may influence behavior and decisionmaking in ways that are more powerful than other media. For example, research shows that people put more credibility in information from computers than information from television and other media (Hawkins et al., 1987), and that some individuals, especially adolescents, often prefer to provide sensitive information to a computer rather than to a physician (Paperny et al., 1990; Lapham et al., 1991; Kinzie et al., 1993; Turner et al., 1998).

Implications of IHC for Health Professionals

The wide availability and use of IHC applications will likely have major implications for health professionals who provide individual- and population-based health services. For clinicians, the major areas of impact are likely to include patient care, the clinician-patient relationship, and the organization of medical systems (HCI, 1994; Kassirer, 1995; OTA, 1995; Blumenthal, 1997).

Patient Care

The premise of clinical decision-support IHC applications is that patient care is participatory and largely patient-directed. In this model, the health professional functions as a facilitator or partner in care rather than as an authority. Although this may come naturally to some health professionals, others will need to develop new strategies of communication rooted in an understanding of their patients' needs and preferred clinical outcomes, and an acceptance of the increasing role and responsibility of patients in decisionmaking. In addition, the use of some IHC applications, such as those that facilitate remote health monitoring and self-care, will require clinicians to take a more proactive approach in identifying health problems and care delivery. It should be noted, however, that regardless of information access, some proportion of people would prefer to relate to their provider as an authority figure rather than on an equal level. One of the challenges for clinicians will be to determine the appropriate balance between their role as an "authority" versus their role as a "partner" for any given patient.

The ability to translate, integrate, or link clinical protocols to IHC applications may impact on patient expectations and provide a powerful way to monitor quality-of-care from the patient's perspective. It is possible that the quality of patient care may be improved by telemedicine-oriented IHC applications that assist real-time specialty consultations, increase access to information databases and continuing education opportunities, and facilitate clinical decisionmaking (Blumenthal, 1997). In addition, these technologies are beginning to have a profound impact on the training of health professionals in patient care both in terms of enabling innovative methods for teaching and developing patient communication skills (Henderson, 1995; MacKenzie and Greenes, 1997).

The Clinician-Patient Relationship

IHC applications that promote peer and emotional support and provide health information through nontraditional channels may be perceived by some to diminish a patient's trust and confidence in, or dependence on, his or her clinician. Information and advice from other information sources, such as online publications reporting new research, or anecdotal sources, such as online chat groups, can be used to challenge—or “second guess”—clinicians (Keoun, 1996a). These factors, the sheer volume of biomedical information produced every day, and the increasing ease of access to health information, create an environment in which the public’s perception about authorities for health information is changing. Physicians and other traditional health professionals may come to be perceived as one of many sources of authoritative medical knowledge, and clinicians may become one of several types of professionals that individuals rely on to help solve a health problem. In some cases, patients may have greater access to information about their conditions than their health care providers.

The above challenges, however, can sometimes lead to greater rather than diminished confidence in health care providers (Gustafson, Robinson et al., 1999). Some IHC applications, such as shared decisionmaking tools and provider-patient electronic communication applications, can enhance the clinician-patient relationship by providing clinicians with valuable insights into patient needs and improving their patient communication skills (Borowitz and Wyatt, 1998). It is also possible that patient compliance with treatments may improve through increased access to information and support. In addition, a recent survey of Californians with Internet access showed that they considered information from their physicians and other health care providers to be the most useful and trustworthy of all information sources, including the Internet (NHF, 1998).

Health Care Systems

The trend to reduce health care costs will increase the demand for IHC applications that promote self-care, enable demand management of services, and supplement face-to-face interactions with electronically mediated ones. Many health plans already communicate with members through e-mail and Web sites. Deployed as tools to assist with administrative matters, such as changing an address or checking on insurance status, IHC will increasingly be used for health care-related functions, such as remote management of patients (Alemi, 1998). As this evolves, confidentiality and privacy concerns regarding the transmission of personal health information beyond the traditional medical record will be major issues.

In a fragmented health care system, IHC applications have potential to help integrate service delivery by enhancing provider communication and centralizing information resources. It is also possible that, as health care delivery increasingly relies on information technology to maximize efficiencies, smaller health plans that cannot invest as heavily on technology as the better capitalized plans will become less price competitive. On the other hand, implementing cost-effective IHC applications may allow smaller health organizations to be more competitive because they do not have large physical plants to maintain and support.

As health care delivery systems look to further reduce costs, some components of care delivery may be reassigned from relatively expensive professionals, such as physicians, to less costly providers, such as nurses and other health professionals. This may already be happening as new types of professionals such as “care managers” or “health resources specialists” who have substantial skill at finding and coordinating resources, are beginning to emerge to assist patients. The delivery of health information and education, once under the purview of physicians, may be delegated to expert “communication/ information specialists,” redefined health educators, or interactive systems. Even if this only occurred within a small segment of the population, the “disintermediation” of the traditional “mediators” of health care would represent a major shift in roles and responsibilities for many clinicians (Blumenthal, 1997).

Public Health Systems

The application of information technology to public health systems is likely to result in profound changes because most of the core functions of public health, such as monitoring health status, diagnosing community health problems, and evaluating personal and population-based health services, are heavily reliant on the collection, analysis, and dissemination of data and information (PHFSC, 1994). IHC applications targeted for public health professionals could facilitate communication between the health care and the public health sectors and among public health professionals themselves. This may result in improved coordination and integration between the health care and public health systems (The Medicine/Public Health Initiative, 1998), but it also raises significant concerns about data quality.

IHC applications also can improve the reach and use of public health services by increasing awareness of services and expanding community outreach. This may be a particular benefit in rural areas where distance has been a significant barrier to service delivery. If current trends in public demand for health information continue, it is likely that the general public and others will want enhanced access to health data—in terms of both disease risk and health status—on a local and national level. Currently, however, many local health departments do not have the staff, resources, or technical capacity to collect, analyze, and disseminate community health data and information (CDC, 1997; PHF, 1998). Smaller health departments, in particular, may find themselves challenged by balancing the demand for more community-tailored information with finding resources to provide and maintain it. By implementing IHC applications collaboratively, however, local health departments may improve operating efficiencies.

With improvements in the technical capacity of health departments, IHC may become a central strategy for community health education, community outreach for services, and social marketing for positive health behaviors. In fact, some health departments are already developing applications that serve these functions (ASTHO, 1998). For example, providing access to interactive tools that assess and communicate individual disease risk, and provide support for behavior change, can be important initiatives to improve community health. In addition, IHC may have a particular impact on one of the central functions of public health departments—disease surveillance and monitoring of community health indicators. In the future, "disease surveillance" may be blended into a larger system of "health surveillance," and a substantial proportion of health information and data may be generated by routine collection of data from many community settings rather than driven by reports from clinical encounters. This may lead to both more accurate community health monitoring and improved detection of disease outbreaks (O'Carroll, 1997).

Technology Trends and IHC

The technologies underlying IHC are undergoing rapid change and evolution (NAS, 1996). Developers and other stakeholders should be cognizant of how emerging technology trends may influence future applications. Pertinent trends include:

1. The ubiquitous presence of computers and the Internet in society
2. Wide availability and increasing use of computers and the Internet for personal use in the home
3. Dramatic increases in the affordability and portability of network-capable computers and other communication devices increasing justification, given their perceived benefit, for their purchase by the public
4. The emergence of the Internet and the World Wide Web as a means for public access to health information and support (Slack, 1997)
5. The convergence of IHC technologies into a common carrier (the Internet and World Wide Web) and decisions by both public and private sector organizations to support a common carrier for health information (Tifflin and Rajasingham, 1995; Agnew and Kellerman, 1996)
6. The imminent availability of a next-generation, broadband[2] Internet (e.g., Internet2 and the Next Generation Internet) capable of delivering

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[2] "Broadband" refers to network bandwidth that is wide enough to carry advanced services such as high quality motion video. Quality of Service (QoS) is used here to describe the technical quality of media services, such as full motion video, of sufficient quality to support educational goals. Measures of QoS include video window size, frame rate, and the latencies between selecting a video stream and its actually starting, and synchronization between video and audio.

high Quality of Service (QoS) and interactive multimedia programming, including full motion video and increasingly engaging and easy-to-use interfaces (Henderson, 1995; Henderson, 1998; Shortliffe, 1998)

7. The emergence of novel methods of information access and analysis, including knowledge repositories (Haynes et al., 1997), intelligent and mobile "agents," "data mining," and "expert systems" as discussed later (Apte, 1977; Kotz et al., 1997; Maes, 1997)

The first four of these trends project an environment in which most users will have access to network-based services, and most will be capable of using them. The last three will have great impact on the kinds of distance learning applications that can be provided. This makes possible learning experiences that are more involving, effective, and efficient than before, as well as information retrieval that is extremely easy or transparent to the user. Next-generation IHC applications may be capable of delivering extraordinary learning experiences to individuals and organizations, independent of time and location.

Developers, purchasers, and policymakers can help set the direction of the application of these technologies, and derive advantage from them. This requires an understanding of the underlying technologies and how they can be applied, research on the current and future state of the infrastructure, and the actual application of technologies and tools to improve infrastructure for personal and public health.

Agents, Data Mining, and Expert Systems

Agents are information-processing programs that can act autonomously and adapt to a user's needs. They are aimed at reducing "information overload" and facilitating the information-retrieval process. For example, agents can simplify interfaces by eliminating steps or choices that a user must make after several encounters with a system. Agents can facilitate use of complex databases by translating arcane database queries into user-friendly dialogs. They also can automate tedious searches for new information by performing searches in the background until new information is located and identified as potentially useful. In addition, mobile agents are programs that can migrate from machine to machine. This allows complex queries to be done at the location of a large database without downloading that database to the user's workstation over slow channels. The particular advances that allow agents to perform such tasks are in the areas of machine learning, information retrieval, high-level scripting languages, graphical interfaces, and generic World Wide Web technology.

The rate of growth of information content on the Web, in the technical literature, and implicitly in electronic records may overwhelm people who wish to use health-related information. Through use of information retrieval and Web technology, it may be possible to build agents that can constantly monitor several databases and other repositories of information for new material pertinent to a provider's needs and areas of expertise. When that information is identified, the agent formats it into a natural presentation and notifies the user of its availability.

By design, agents move much of the tedium and complexity of information gathering and correlation into the background so that a novice can easily begin using more powerful capabilities. Developers have already demonstrated such agents with Web "clipping" services that utilize user-friendly interfaces and e-mail systems. Furthermore, it is possible to program agents that gradually adapt to a user's experience by creating shortcuts and anticipating actions based on prior usage. This property of agents arises from the design of the agent system by understanding the needs of users and building systems that amplify the users' abilities without forcing new processes onto them.

The emergence of expert systems has important implications for IHC development. Potentially, for example, they could help users self-diagnose their conditions and even select from a variety of available treatment options. One powerful feature of expert systems is that they can improve themselves over time if they can collect data on the accuracy of their earlier conclusions and recommendations. Such systems have great potential for improving participation in health care and empowering consumers. They also have the potential to reduce costs-of-care by allowing, over the long term, consumers to manage their own care rather than relying on clinicians.

To date, however, expert systems have not lived up to their promise. They frequently have not been as accurate as expected in the conclusions they reach. Hence, such systems need to be very carefully evaluated in a wide variety of applications before they should be made available for such important decisions as diagnosis and treatment selection. Moreover, because they often are systems whose underlying structure changes over time, their evaluation would need to be ongoing. Even so, expert systems will likely be a fundamental component of IHC applications that enhance self-care and reduce health care costs.

It is likely that some automated tools will be built into applications to assist in the assessment of quality and maintenance of information. Because tailoring of information in automated systems may involve complex algorithms and databases can be automatically updated by agents, the ability of people to adequately evaluate these IHC applications may be compromised, and research and development on this issue are needed. This and other evaluation issues are discussed more fully in Chapter IV.

III

Underlying Evidence and Science of IHC

An evidence-based approach to IHC application design is grounded on developing applications by taking into account the best available evidence from research and generally accepted theories and concepts of behavior change and decisionmaking (Jadad, 1998a). Stakeholders, especially health professionals and purchasers of IHC applications, should be familiar with the social science concepts commonly employed in application design. Social science theories, models, and evidence from research provide guidance about important design considerations, such as the characteristics of individuals, ways in which people process information, and likely consequences of behavioral change strategies. Understanding these theories, models, and evidence from research is also helpful in critically appraising the true value of an IHC application. For example, without knowledge of these concepts, the use of technologies that appeal to the senses may distract someone from focusing on application content or on the evidence-based methods employed. Utilizing the latest technology is not sufficient when the content or approach is inappropriate. In this section, the Panel briefly reviews major psychological theories and models frequently used by developers in selecting appropriate content, media, and methods.

Psychosocial Theories and Models and IHC Design

No unified theory exists to provide direction in IHC application design and development. Rather, a variety of social science theories and models effectively describe how people think, reason, act, and make choices. These theories and models can help illuminate the processes related to health-related behavior change and decisionmaking. They include: the theory of reasoned action (Ajzen and Fishbein, 1980; Ajzen, 1991); theories of learning (Bandura, 1986); group decisionmaking (Janis and Mann, 1977); transtheoretical stages of change (Prochaska et al., 1992; Prochaska et al., 1994); decision analysis (Weinstein et al., 1988; Mulley, 1989); and other theories and models (Rosenstock, 1974; Nisbett and Ross, 1980; Petty and Cacioppo, 1986; Locke and Latham, 1990; Strecher and Rosenstock, 1998).

Social science models that describe cognitive and behavioral concepts, and the relationships between these concepts, provide important orientation to designers of IHC applications. Listed below are selected psychosocial concepts with illustrative examples of IHC applications that may be of particular relevance to developers.

1. *Outcome expectations associated with the behavior in question*—Outcomes (both positive and negative) one expects as a result of engaging in a particular behavior.

   Theories: (Rosenstock, 1974; Ajzen and Fishbein, 1980; Bandura, 1986; Weinstein, 1988; Ajzen, 1991; Prochaska et al., 1992; Strecher and Rosenstock, 1998)

   IHC Applications: (Velicer et al., 1993; Campbell et al., 1994; Skinner et al., 1994; Strecher et al., 1994; Brug et al., 1996; Dijkstra et al., in press)

2. *Self-efficacy expectations*—Confidence in one's ability to engage in a particular behavior.

   Theories: (Bandura, 1986; Strecher et al., 1986)

   IHC Applications: (Campbell et al., 1994; Dijkstra et al., in press)

3. *Goal setting*—Setting goals for change.

   Theories: (Locke and Latham, 1990; Strecher et al., 1995)

   IHC Applications: (Strecher et al., 1995)

4. *High-risk situations*—Situations that trigger a particular behavior.

   Theories: (Shiffman, 1996)

   IHC Applications: (Shiffman et al., 1997)

5. *Attributions for previous failures*—Interpretations one makes for the causes of previous failures in changing a particular behavior.

   Theories: (Foersterling, 1986; Weiner, 1986)

   IHC Applications: (Strecher et al., 1994)

6. *Stage of change*—Degrees of motivation and current experience in changing a particular behavior, ranging from precontemplation, contemplation, preparation, and action to maintenance.

Theories: (Weinstein, 1988; Prochaska et al., 1992)

IHC Applications: (Velicer et al., 1993; Campbell et al., 1994; Skinner et al., 1994; Strecher et al., 1994; Brug et al., 1996; Dijkstra et al., in press)

7. *Prescriptive decision theory*—Use of explicit quantitative estimates of probabilities of good and bad outcomes, and the utilities of those outcomes from the decisionmaker's perspective to inform a decision; and descriptive decision theory—Modeling decisions in the face of uncertainty in an attempt to predict actual behavior (e.g., prospect theory).

   Theories: (Mulley, 1989)

   IHC Applications: (Brennan, Moore et al., 1995; Gustafson, Hawkins et al., 1999)

Several psychosocial concepts that are particularly important in IHC application development are empowerment, self-efficacy, and motivation. Empowerment can be generally defined as the process that enables people to exert control over their lives and their destinies (Peterson and Stunkard, 1989; Feste and Anderson, 1995). It is closely related to health outcomes in that powerlessness has been shown to be a broad-based risk factor for disease. Studies demonstrate that people who feel "in control" in a health situation have better outcomes than those who feel "powerless" (Israel and Sherman, 1990; Anderson et al., 1995). Empowerment can be enhanced by online support groups that allow patients to feel "connected" to others with a similar health condition (Gustafson et al., 1992; Pingree et al., 1993; Gustafson, Hawkins, Boberg, Bricker, Pingree et al., 1994). Interactive self-assessment tools can also help in this regard by helping individuals focus on central issues. Similarly, self-efficacy is a person's level of confidence that he or she can perform a specific task or health behavior in the future (Bandura, 1977; Holman and Lorig, 1987; Lorig et al., 1989). Clinical studies show that self-efficacy is most predictive of improvements in patients' functional status (O'Leary, 1985; Cunningham et al., 1991). Perceived self-efficacy has been shown to play a significant role in smoking cessation relapse rates, pain management, control of eating and weight, success of recovery from myocardial infarction, and adherence to preventive health programs (Strecher et al., 1986; Mullen et al., 1987; O'Leary et al., 1988; Allen et al., 1990; Maibach et al., 1991).

Motivation is a major factor in explaining the effectiveness of any instructional event, especially those that are voluntary and dependent upon intrinsic (as opposed to extrinsic) motivation as many IHC contexts are. Attribution theory states that the degree to which people attribute their own successes or failures to ability, effort, task difficulty, or luck differentially predicts whether, to what degree, and what kinds of subsequent learning opportunities they will voluntarily seek (Dweck and Leggett, 1988). Differences in attribution (e.g., “I achieved because I made the effort” versus “I achieved because the test was easy”) explain why some people feel in control of their learning whereas others feel helpless in learning. For example, if when searching online to learn about treatment options, a person experiences difficulty, and he or she usually attributes success or failure to blind luck, the person may feel the task is just too difficult and/or his or her luck has run out. As a result, the person may give up and not seek online help again. On the other hand, another person may experience the same difficulty, but because the person attributes his or her success to effort, this individual persists and continues to use online resources. One of the shortcomings with attribution theory and other motivation theories is that little is known about whether these are “trait” variables or “state” variables. Someone whose motivation might be quite low in a classroom context might be much more motivated by online instruction, indicating that their motivation is a “state” variable. On the other hand, some people are not motivated by any learning opportunity, indicating a “trait” variable. Attribution theory is related to the “confidence” factor in Keller’s ARCS model, which is designed to help developers be more attentive to the motivation aspects of their instruction (Keller and Suzuki, 1988).

Use of the above theories and models as the bases for IHC application development may also contribute to their further development. Interactive media may allow researchers to collect better and different kinds of data on behavior change processes—data that could lead to more refined or comprehensive theories and models.

Behavior Change and IHC Design

Almost all IHC applications seek to change individual behavior. They may lead to better health status, healthy lifestyles, or more appropriate uses of health services. In all cases, positive change is the goal. As described above, many behavior change theories have been developed and tested and all of them involve the use of one or more of the following concepts that are relevant for developers.

1. *Motivation for change.* Users need to believe that they cannot continue with their current behaviors. In some cases, this is a forgone conclusion because the user’s life is suddenly out of control due to an illness or injury. In other cases, the user’s motivation for change needs to be increased. This is the case for primary prevention efforts such as smoking prevention with teenagers. As mentioned above, a developer’s understanding of an intended user’s motivation for change is an important determinant of application effectiveness.

2. *Superior alternative.* Users need to believe that the proposed behavior change will improve their situations. Hence, a woman with breast cancer needs to believe that regular arm exercises after surgery will enhance her arm mobility. Developers need to be very clear about what changes they hope to achieve and design programs that help users to believe that such changes will address their pressing and long-term needs.
3. *Social support.* People facing significant life transitions or health problems, or those adopting complex behavior changes, often experience stress. When they do, they need the support of others who care about them and have experienced similar problems. Emotional support may help them overcome setbacks and renew their commitment to change. Developers need to build in mechanisms for emotional support to help overcome stress.
4. *Skills and self-efficacy.* Changes often require new skills or the application of old skills in new settings. In both cases, users need to not only know these skills but also have the confidence that they are capable of implementing them in different settings. Developers may need to build into their program opportunities to learn and practice such skills.
5. *Plan.* Change is difficult. The simpler the change, the easier it will be to adopt. A well-thought-out, easy-to-implement, and well-documented plan should be the centerpiece of change efforts. Developers hoping to effect change among users should include simple and easy-to-use implementation plans.
6. *Pilot tests.* Most changes fail the first time—and often several times—when they are implemented before becoming an effective part of a user’s life. It is essential that the user learn from the failures and continue working toward change. Developers should expect this and set up mechanisms to allow the user to fail safely and to learn in the process.
7. *Monitoring and feedback.* An important part of learning from failure is to have a monitoring mechanism that allows users to track their behaviors and the impact of their behaviors and to give feedback, not only to themselves but also to developers. Developers should build into their applications effective feedback mechanisms that will allow them to learn from users and to assist users to learn from their experiences.

Evidence on Impact and Effectiveness of IHC

Evidence from research on health communication interventions, technology-based approaches to communication, and other discrete elements should be taken into account by developers, sponsors, evaluators, and users of IHC.

Some health communication interventions have been shown to be efficacious (Robinson, 1989; Campbell et al., 1994; Gustafson, Hawkins, Boberg, Bricker, Pingree et al., 1994; Strecher et al., 1994; Balas et al., 1996, 1997; Krishna et al., 1997; Shiffman et al., 1997), but research on the effectiveness of computer-based approaches is limited. In fact, most applications have not been evaluated for effectiveness. Only a small number of studies have examined the effectiveness of IHC applications in improving health status indicators (AHCPR, 1997). Of these, only a few were randomized controlled trials (Robinson, 1989; Brennan et al., 1995; Chewning, 1996; Barry et al., 1997; Morgan et al., 1997; Brennan, 1998; Gustafson, Hawkins, et al. 1999).

The potential effectiveness of IHC also is suggested by research on related discrete elements. Studies show that access to health information can enable patients to be more active participants in their care and lead to better medical outcomes (Greenfield et al., 1985; Brody et al., 1989). Patients report that they want to be informed about their medical condition (Korsch, 1984; Mahler and Kulik, 1990). The process of sharing information enhances the doctor-patient relationship. In addition, research on the effectiveness of various formats and types of media for conveying health information generally indicates that video and slides are more effective than books and audiotapes in educating consumers (Alterman and Braughman, 1991; Funnell et al., 1992; Gillipie and Ellis, 1993; Consoli et al., 1995).

The following sections examine the potential impact of IHC on satisfaction and relationship with providers, health care practice patterns, personal lifestyles, and utilization of health services.

Impact on Satisfaction and Relationship With Providers

Users are generally satisfied with IHC applications (Hassett et al., 1992). This is not surprising, because dissatisfied users are unlikely to utilize them and therefore may not be represented in studies of satisfaction. A better picture of satisfaction with IHC emerges when level of use is examined. Average use of IHC applications is high, especially for electronic support groups. For example, one study reported that, during one-year of study, caregivers of persons with Alzheimer's disease used electronic support groups twice per week for an average of 13 minutes (Brennan et al., 1995). Similarly, another study reported that cocaine-using pregnant women used electronic services over a 7-month period an average of 3.2 times per week (Alemi, Stephens, Javalghi et al., 1996). Extensive use of IHC applications may indicate user satisfaction.

The impact of IHC on overall satisfaction with the health care system is not well understood. Some data suggest that when patients have access to both online and face-to-face counseling, they prefer online counseling. For example, in an unpublished study of recovering patients who had access to both online and outpatient substance abuse treatment, 30 percent presented for outpatient treatment and 87 percent accessed online treatment (Mahboeba Mosavel, TelePractice, Inc., personal communication, September, 1998). A randomized study of postpartum mothers showed that they were eight times more likely to use electronic support groups than face-to-face groups (Alemi, Mosavel et al., 1996). Another study showed that women with breast cancer preferred online counseling and support groups to face-to-face interactions (Gustafson et al., 1992).

The above studies suggest that use of—and, by inference, satisfaction with—face-to-face interactions may decrease when electronic-mediated options are available. One study, however, reported that IHC applications could improve patients' confidence in their physician (Gustafson, Hawkins et al., 1999). These seemingly contradictory findings may be dependent on the extent of integration of IHC with face-to-face services. When electronic-mediated and face-to-face visits are closely integrated (e.g., both interactions are with the same clinician), then IHC may increase satisfaction with face-to-face services. When online and face-to-face encounters are not fully integrated, then online services may reduce satisfaction with face-to-face visits. In some cases, however, online encounters may strengthen trust in regular health care providers if online encounters reaffirm the advice of such providers.

Integration of online and face-to-face services is also related to providers' attitudes towards online services. Health care providers' satisfaction with IHC is not well documented. One of the few studies available surveyed 325 members of the American Association of Diabetes Educators about their preferences for different methods of education including books, videotapes, computer-based programs, and audiotapes (Funnell et al., 1992). Providers were least enthusiastic about computer-based applications, but this finding may reflect the quality of early IHC applications. Providers' negative reaction to IHC is surprising in light of the findings that patients generally prefer IHC to other forms of health communication (Alemi and Higley, 1995), and evidence that IHC applications can be effective in changing patient behaviors.

It is possible that many providers have not been exposed to high-quality applications, and their attitudes may change once they use them and become more involved in discussions about IHC. Some providers' negative attitudes toward IHC, however, may be a function of the difficulties they face in integrating these technologies into their practices (Alemi, 1998). Effective implementation of IHC applications requires not only substitution of, or integration with, educational books and pamphlets but also changes in the way clinicians interact with patients. The very nature of clinical visits changes when information can be tailored to the patient's condition; when some components of care, such as education, can be completed before or after the visit; or when follow-up care can be accomplished without an office visit.

Impact on Health Care Practice Patterns

The impact of IHC on patient behavior may be an indirect result of changing provider practice patterns. Patients may interact with IHC applications but the results of these interactions are shared with providers who may change their advice to the patient. Good examples of such applications include shared medical decisionmaking and informed consent applications. Studies show that multimedia applications can be used to assess patient preferences (Barry et al., 1995; Jimison et al., 1998), but limited data are available on the effectiveness of shared decisionmaking applications in changing practice patterns.

Another way practice patterns might be affected by IHC applications is through computerized history taking. Studies show that people may be more likely to be truthful to a computer than to a clinician (Erdman et al., 1985). One study found that patients donating blood were more likely to report their HIV-related risk factors to a computer than to a clinician (Locke et al., 1992). These studies suggest that IHC may solicit more accurate information that ultimately changes clinical decisions and courses of treatment.

IHC also may change practice patterns by improving the efficiency of clinical visits. In one study, patients were interviewed by a computer before their visits. Findings were put into patient medical records and made available to attending clinicians (Lloren, 1998). Clinicians were not only satisfied with this service, but also thought that it had changed their practices in a positive way. Independent verification showed that these clinicians were detecting 15 percent more alcoholics than the clinic's average detection rate.

Impact on Personal Lifestyles

Several studies show that mass media can effect behavior change among communities. For example, one study showed that 26 hours of mass media promotion of healthy behaviors led to a 16 percent reduction in cardiovascular risks across a community (Farquhar et al., 1990). Although mass media are not interactive, to the extent that online communications are evolving into mass media, they may be effective in bringing about widespread behavior change. With the advent of "push" technology, multimedia and video, online applications are becoming increasingly similar to established mass media, such as broadcast television.

IHC can change health behaviors, but not all applications have been successful in bringing about such change (Fitzgerald and Mulford, 1985; Alterman and Braughman, 1991; Brennan et al., 1995; Consoli et al., 1995; Balas et al., 1997). Furthermore, the impact of IHC on health behavior is not always sustained. No single health education/communication intervention has been shown to be effective in changing behavior over a time period; there is no "magic bullet.” For example, one study found that computer-based instruction improved smoking quit-rates for 6 months but not for 18 months post-baseline (Lando et al., 1997). It is possible that some IHC applications have not had a lasting impact on behavior change because information alone is not sufficient for behavior change. Health education has been shown to be more effective when combined with other supporting interventions. For IHC, this reinforces the need to combine information with interactive role-playing and peer support through electronic bulletin boards. IHC applications that have integrated health information, role-playing, and support groups, have been successful in bringing about behavior change (Alemi et al., 1989; Gustafson et al., 1992).

Health education also can be made more effective by tailoring the information to key issues and patient characteristics. For example, smokers who received a letter tailored to their circumstances were more likely to quit than those who received a general message (Strecher et al., 1994). Similar results were obtained for people trying to reduce their fat intake (Campbell et al., 1994; Watkins et al., 1994).

Given that people face multiple sources of information, computerized health education is more likely to be effective when the effort is frequent and sustained over time; however, the effectiveness of brief interventions may eventually diminish. Growing evidence suggests that there must be a minimal level of interaction before the IHC can have a measurable impact on behavior. In one study, for example, no beneficial impact was measured unless people had used the system at least three times per week over a 7-month period (Alemi, Stephens, Javalghi et al., 1996). Benefits were observed for patients with even higher use patterns in another study (Taylor and Gustafson, 1998). Although both of these studies involved self-selected users, they suggest that impact of IHC may be more pronounced when patients use the service at least three times per week. Another study, however, found that it was not the amount but the type of use that most affected outcomes (Smaglik et al., 1998). Patients who had a clear purpose for using an IHC application benefited more than people who used it more often but did so in an undirected manner, and more than those who only used the application’s support group functions.

It is possible that there is a positive “dose-response” effect with certain types of IHC applications. However, one study has raised the possibility that greater use of the Internet may lead to declines in face-to-face communications with family members and increases in depression and loneliness (Kraut et al., 1998). Randomized studies are needed to clarify the relationship between exposure to IHC and positive behavior change and potential related side effects.

Impact on Utilization of Health Services

IHC may have a positive impact on utilization of resources either by reducing use of unnecessary services (e.g., use of emergency rooms for non-urgent problems) or by increasing use of cost-effective services (e.g., immunizations). Health education can reduce unnecessary health care visits (Fries and McShane, 1998), and there is evidence that IHC applications can have a similar impact. One study compared randomly assigned groups of university students who did or did not receive computerized health education (Robinson, 1989). The group that was exposed to the intervention had a 22.5 percent lower rate of medical visits than the group that did not receive the application.

Of particular interest is a randomized control study involving 204 HIV-infected patients (Gustafson, Hawkins et al., 1999). The experimental group was provided access to an IHC application with multiple functions, including online peer support. Computer-mediated social support was the most frequently used function of the application. Investigators found that patients with access to the application, as compared to control patients, were more likely to report higher quality-of-life in several dimensions, including social support and cognitive functioning. They also had shorter time-per-visit to ambulatory care, and less frequent and shorter hospitalizations than the control group. The experimental group had lower total health care costs than the control group.

In another study, voice-based electronic support groups were compared to face-to-face support groups (Alemi, Mosavel et al., 1996). Over time, the groups that met online were eight times more likely to meet than other groups. Furthermore, subjects who used the electronic bulletin boards were less likely to visit a health care provider. Reduced visits did not impact on health status. This study suggests that electronic support groups may help reduce inappropriate use of health services.

The above studies support the importance of IHC in bringing about behavior change and show that use of electronic support groups can lead to substantial reductions in use of services and cost-of-care in certain groups.[3] Because no studies have examined the cost-effectiveness of IHC applications in large populations, however, the cost-effectiveness of employing IHC versus traditional health communication media in the general population is unknown.

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[3] Other forms of communication, such as telephone-based interventions, also can reduce cost-of-care. In a very successful trial, investigators replaced face-to-face, follow-up visits with three scheduled telephone calls (Wasson et al., 1992). Over a 2-year period, estimated total expenditures for “telephone care” were 28 percent less per patient compared to the usual care patients.

Other examples of how IHC applications may influence utilization of health services are applications that focus on reminding patients (Austin et al., 1994). With some exceptions (Austin et al., 1994), when computers call to remind parents to visit a clinic, on-time immunization and vaccination rates improve (Brimberry, 1988; Linkins et al., 1994; Dini et al., 1995; Alemi et al., 1996; Lieu et al., 1998). These data suggest that IHC applications can affect health outcomes by encouraging patient compliance with scheduled visits.

Use of IHC applications, however, does not always lead to lower utilization of services. The impact of these applications on utilization and cost-of-care may depend on the effectiveness of the application and the message being communicated (Bass et al., 1998). If the content encourages a visit, then more visits are likely. If messages are neutral (as in electronic support groups) or discourage visits (as in messages encouraging self-care) then IHC applications may reduce visits.

Potential Areas for Effectiveness Research

A comprehensive review of the scientific literature on consumer health informatics related to patient decisionmaking concluded that, because of the relative paucity of studies in this area and their varying methodological quality, it was not appropriate to draw solid conclusions about the effectiveness of these applications in reducing costs, improving health outcomes, or in regards to other important measures (AHCPR, 1997).[4] The authors identified four priority areas for research:

- Assess the effects of informatics tools on a full range of outcomes
- Identify factors that influence use of informatics tools
- Assess effects of informatics tools on patient-clinician communication
- Assess the cost-effectiveness of different types of patient informatics tools

After examining the methodologies employed by researchers in this area, the authors also proposed the following lessons for future research in this area (AHCPR, 1997):

- Describe the nature of the implementation and use of informatics tools
- Develop clear hypotheses about measurements
- Provide adequate length of follow-up

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[4] The authors of this report used the term “informatics tools” to refer to tools that “describe and present information regarding screening or treatment alternatives in order to help patients in making decisions about alternatives.” The authors examined both interactive computer-based tools and noninteractive tools such as brochures.

- Incorporate a no-treatment or minimal-treatment control group
- Provide adequate sample size to assess effects among key subgroups

In addition to the above guidelines, the Panel emphasizes the need to select a truly representative sample of the population to study and avoid use of self-selected participants. Research efforts in this area should also incorporate strategies to avoid important sources of bias identified in biomedical research (Jadad, 1998b; Jadad and Rennie, 1998).

Measures of Effectiveness

Valid, reliable, and sensitive measures of IHC effectiveness are limited. Existing measures of effectiveness may not be specific enough to detect some program effects. There are many outcome measures with proven reliability and validity (e.g., the SF-36 or the FACT cancer quality-of-life scale) (Ware et al., 1994; Brady et al., 1997; McQuellon et al., 1997), but these may not be appropriate for evaluating all IHC applications. Outcome measurement scales often combine several statistically related but conceptually different elements and an application's effect on one variable may be diluted by its lack of effect on another. For example, a scale from an instrument of proven validity and reliability examines the physician-patient relationship by inquiring about patients' confidence in their physician and their perceived availability of the physician. An application intended to improve confidence but not physician availability may show no or less impact because of a dilution effect occurring with the use of this scale. Developers, therefore, need to precisely define the objectives of their applications before selecting outcome measures. These measures would ideally measure only those effects of interest. An expanded discussion of other challenges to evaluation of IHC applications is presented in the next chapter.

Factors That Influence Application Design

Several user-related factors may determine developers' selection of application content, interfaces, media, and approaches (Jimision et al., 1999). In designing effective applications, awareness of individual characteristics, preferences, and other individual factors are critical. The explicit involvement of members of the target audience in application design is often essential to a successful product. Developers are frequently challenged to implement specifications that can both meet individual needs and accommodate a wide variety of users.

Individual Characteristics

Individual characteristics, such as age, gender, disability, race and ethnicity, cultural factors, and socioeconomic status, may influence health-information-seeking behavior, and can account for differences in the amount and type of health-related information and support that individuals seek. Some people do not seek much information or support, and others who do may encounter serious barriers to the use of IHC applications (Eng et al., 1998). Willingness to use health information technology may also be an important consideration in designing IHC applications. Individual characteristics and preferences can be accommodated by "tailoring" content and interfaces. Ensuring accessibility of an application's interface is essential to reach users with physical disabilities (WWW Consortium, 1998). Tailored information has been found to be more effective in providing consumer information (Mullen et al., 1985; Skinner et al., 1993, 1994; Strecher et al., 1994; Brennan et al., 1998) and is preferred by patients (Jimison, Fagan et al., 1992). Some users, however, may resist over-customized applications that are too narrowly focused.

Individual Preferences

The concept of individual preferences is important for IHC applications that focus on health decisionmaking (Mulley, 1989; Barry et al., 1988, 1995). Although patients need information about the quality-of-life associated with the medical outcomes of possible decisions, reliable assessment of individual preferences and risk attitudes for clinical outcomes are probably weak links in clinical decisionmaking. Recent efforts to explore the use of computers in communication about health outcomes and in assessment of patient preferences for various health outcomes have started to address these issues (Jimison and Henrion, 1992; Goldstein et al., 1994; Nease, 1994). Information on patient preferences is important for tailoring information to patients and for providing decision support (Jimison, 1997). In addition to differences in preferences for health outcomes, patients differ in the degree to which they choose to be involved in decisionmaking. Age (younger more than older persons), gender (women more than men), and education level (higher-educated more than less-educated persons) are generally strong predictors of desire to be involved in medical decisions. In addition, there is a greater desire to be involved in decisions in health areas that generally require less medical expertise, such as a knee injury, than those that are more complex, such as cancer (Thompson et al., 1993).

Literacy

An individual's reading ability impacts on application design. The problem of low literacy skills is widespread in the United States (Holt et al., 1990; Reid et al., 1995; Baker et al., 1996), and about one of every five adults reads at or below the fifth grade level. Only about half of people examined comprehended written health education materials and average reading levels were well below what is needed to understand standard health brochures (Morgan, 1993; Davis and Mayeaux, 1994; Feldman and Quinlivan, 1994; Baker et al., 1996). Additionally, an analysis of medical information on Web sites showed that, on average, materials were written at a 10th grade reading level, which is not comprehensible to the majority of people (Graber et al., 1999). Lack of health literacy may be an acute problem among the elderly (Gazmararian et al., 1999).

A person who has completed a certain grade level should not be assumed to be able to read at that level. Generally, health materials should be written at least three grade levels lower than the average educational level of the target population (Jubelirer and Linton, 1994). There is a danger, however, that excessively simplifying materials may reduce the value of the program to more educated users. Interactive media can help in this situation because they can be used to accommodate a range of users with varying levels of health and technology literacy. Text characteristics and organization and clarity also impact on comprehension and retention of material (Reid et al., 1995). To address shortcomings in reading literacy, multimedia techniques can be used to facilitate comprehension. Information can be conveyed through video, audio, and graphics, in lieu of text. Additionally, presenting material in multiple languages would increase comprehension for non-native English speakers.

Point-of-Access

The ideal point of access for many of the functions of IHC (as discussed in Chapter II) is the home because this allows the user to access the application at any time of day, in privacy and comfort. However, some applications can function effectively in more public settings, such as schools and worksites. For example, shared decisionmaking applications, because of their typical one-time-use nature, may function effectively through these and other access sites, including libraries and health professional offices. Disease coping and behavior change applications that offer both information and emotional support, however, need to be immediately accessible at any time. Hence, to be used effectively, they need to be available in the home and/or portable. In addition, access to the Internet at work and home expands the availability of online employer-sponsored wellness programs that traditionally were only available at worksites.

Public access points need to be selected with a thorough understanding of the target audiences and will depend on the type of application and the relationship between intended users and the setting. For instance, many underserved populations harbor a distrust of certain institutions that might otherwise be appropriate candidates for delivering IHC applications. If government-sponsored sites, such as clinics and public buildings, are not trusted by these populations, then alternate settings, such as community centers and places of worship, may need to be considered.

Hardware, Software, and Bandwidth

The capability and performance characteristics of the hardware and software and communication pathways used by target audiences to access IHC applications are important considerations for application design. The functions and content of the application should be matched to the level of technology available to typical users. For example, integrating extensive graphics or full motion video into an application that is intended for groups of users who do not typically have computer graphics accelerators or large bandwidth access is counterproductive. The quality of a user's experience when accessing an interactive application via a slow dial-in modem versus a much faster T1/T3 connection is so different as to almost render them as different programs.

IV

Evaluation Of IHC Applications

The Panel considers widespread evaluation as the primary mechanism to improve quality of IHC. Evaluation is the examination of evidence in a way that provides a full perspective on the expected quality, nature, experience, and outcomes of a particular intervention. The purpose of evaluation is to systematically obtain information that can be used to improve the design, implementation, adoption, re-design, and overall quality of an intervention or program. This chapter provides some fundamental background information about evaluation for developers and purchasers and others who may have to conduct evaluations or interpret evaluation results.

Types of Evaluation

The design and implementation of an evaluation typically depends on its purpose, the status of the intervention, and the type of decision the evaluation is intended to address (Rossi and Freeman, 1993). The process of evaluation can be defined in the following stages.

1. *Formative evaluation* may be used in the early stages of development to assess the nature of the problem and the needs of the target audience(s), with a focus on informing and improving program design and ensuring accuracy of content.
2. *Process evaluation* may be used during application development and implementation to monitor the administrative, organizational, or other operational characteristics of the development and implementation

processes.

3. *Outcome evaluation* may be used to examine an intervention's ability to achieve its intended effect under ideal conditions (i.e., efficacy) or under real-world circumstances (i.e., effectiveness) and its ability to produce benefits in relation to costs (i.e., efficiency or cost-effectiveness). Traditional evaluation models may not adapt easily to rapid changes in IHC application design and implementation. For example, because the content of a health-related Web site can change rapidly, tests of effectiveness may quickly become outdated. With technology sectors, such as e-commerce, evolving dramatically, even process evaluations of implementation strategies may become outdated before they are finished. Because of the need for continuous quality improvement, more active and flexible models of evaluation may be more appropriate for IHC applications. There are many approaches to evaluation; selection of an appropriate method depends on the purpose of the evaluation and what is being evaluated. Discussion of all these methods is beyond the scope of this report and more details can be found elsewhere (Freidman and Wyatt, 1997).

The formative, process, and outcome evaluation model might be amplified by another perspective derived from training evaluation. Five levels or facets of evaluation for IHC can be conceptualized (Figure IV-1).

1. *Level 1* would be "engagement and appeal" or reaction to the application with the intent of finding out whether audiences use and value an IHC application.
2. *Level 2* would be "learning" with the intent of finding out whether audiences learned any knowledge, skills, and attitudes from the application.
3. *Level 3* would be "behavioral change" with the intent of finding out whether the audiences have applied their new knowledge, skills, and attitudes in the real world.
4. *Level 4* would be "impact" with the intent of revealing whether the changed behavior actually improved health status, reduced illness, reduced costs, or had other desirable effects.
5. *Level 5* would be "return on investment (ROI)" with the intent of finding out whether the impacts that have been achieved have more value than the costs of developing and maintaining the IHC application.

Figure IV-1. Five Levels or Facets of IHC Evaluation

Level of Evaluation	Key Evaluation Questions
Level V: Return on Investment (ROI)	Did the benefits of the application exceed its costs?
Level IV: Impact	Did the application have any benefits?
Level III: Behavior Change	Did users change their behaviors?
Level II: Learning	Did users' knowledge, skills, and attributes improve?
Level I: Engagement and Appeal	Did users like the application?

Adapted from: Kirkpatrick DL. *Evaluating Training Programs: The Four Levels.* San Francisco, CA: Berrett-Koehler Publishers, 1994; and Phillips JJ (Editor). *Measuring Return on Investment: Eighteen Case Studies From the Real World of Training.* Alexandria, VA: American Society for Training and Development, 1994.

From the perspective of many stakeholders, particularly purchasers and users, evaluation of a proposed health intervention may focus on the central question, "Does this intervention provide enough measurable positive outcomes to justify the cost?" There are no widely accepted standards for measuring outcomes and costs associated with IHC applications. The Panel on Cost-Effectiveness in Health and Medicine, however, recently developed a framework for cost-effectiveness analyses that is applicable for the assessment of any health intervention (PCEHM, 1996; Russell et al., 1996). Their technical guidance may be helpful for developers and evaluators of IHC applications. Outcomes to be measured for any intervention should include both benefits and harms associated with the intervention. In assessing the total costs of an application, it would be appropriate to include costs associated with any change in both health- and nonhealth-related resource uses. For IHC evaluations, both actual costs of pilot projects and projected costs of large-scale implementation of the application should be considered.

Distinction Between Evaluation and Research

Research and evaluation are components of a continuum of disciplined inquiry that are driven by different goals. Research generally has two types of goals: theoretical and empirical. Research with theoretical goals is intended to explain phenomena through the logical analysis of the results of scientific investigations and the synthesis of these results, along with theories and principles from other fields and original insights, to develop new or refine existing theory. Research with empirical goals is intended to determine how and why phenomena occurs by testing hypotheses related to theories, eventually leading to increased capacities to describe, predict, and control phenomena. Evaluation, however, generally has two different types of goals: formative and summative. Evaluation with formative goals is intended to support the development and improvement of innovative solutions to problems. Evaluation with summative goals is focused on estimating the effectiveness and worth of a particular program, product, or method for the purpose of making a decision about it in an applied setting. Typical decisions might be selection, purchase, certification, extension, or elimination.

With a continuum of such goals in mind, the need to make sharp distinctions between research and evaluation is reduced. One issue that must be clarified is that rigor and discipline are not necessarily distinguishing features between research and evaluation. The research to evaluation continuum represents a shift from theoretical goals to goals that are more action-oriented. Research is generally focused on adding to the body of knowledge about phenomena, whereas evaluation is usually focused on solving particular problems; rigor and discipline are important aspects of both.

Qualitative Methods and Statistical Process Control

Evaluation methods often focus on the need to prove rather than explain an effect. Hence, resources are allocated toward large sample sizes and with a focus toward one- or two-time assessments of effect. Such strategies are appropriate for addressing stable applications whose effects need to be demonstrated beyond doubt. However, the field of IHC is evolving and the content and even structure of applications will change to keep up with new knowledge. Moreover, because IHC is in its infancy, the goals of evaluation should be to not only determine effectiveness but also to guide improvements. This implies the need for evaluative efforts that explain effect, offer guidance for improvement, and monitor the changing nature of IHC over time. Toward that end, it may be more valuable to monitor the impact over an extended period of time on a smaller sample of users and to invest resources in understanding why things happened as they did.

Qualitative research methods and statistical process control may be important resources for such evaluation strategies. Qualitative research relies on observation and interviews with stakeholders to better understand the underlying causes of success or failure. This understanding could be very important as ongoing improvements to the application are made. Statistical process control provides a strategy to monitor application performance over time and to identify when the application is moving out of control. Such techniques could help monitor the dynamic nature of electronic support groups and identify whether discussions are having detrimental effects. It could also be useful to detect when there are significant changes in use patterns that may warrant further examination or even intervention. However, these strategies also could be used to assess the effectiveness of IHC applications. Because the applications are of such a dynamic nature and their impact may be a cumulative one, the goal may not be to conclude beyond a doubt at one point in time but beyond a reasonable doubt across the life span of the application.

Potential Benefits of Evaluation

From the perspective of potential stakeholders of IHC applications, the potential benefits of widespread evaluation include the following (Eng et al., 1999):

1. *Improved quality, utility, and effectiveness.* Evaluation allows for the identification of potential problems and provides important feedback for application development and quality improvement. This leads to more effective and useful applications for users. Both positive and negative evaluation results are valuable in advancing the field of IHC. For example, negative results promote development of effective products by reducing resources spent on ineffective approaches.
2. *Reduction of likelihood of harm.* Evaluation of health impact may identify and reduce the use of IHC applications likely to have unexpected harmful effects.
3. *Better use of resources for effective applications*. By informing purchasing and implementation decisions, evaluation can help target resources on effective applications and avert the investment of resources on ineffective ones.
4. *Greater participation of stakeholders in the development and implementation process.* Appropriate evaluation necessitates engaging users and other stakeholders early in the development process. This can increase the probability of a favorable impact on health and quality outcomes.
5. *Improved decisions about applications*. The results of outcome evaluations can help users, purchasers, and others make informed choices about the selection of appropriate and effective applications.

Developers of IHC applications also may benefit substantially from adopting a norm of evaluation (Henderson et al., 1999). From their perspective, evaluation may improve their chances of success in the following ways:

1. *Increased sales and market share.* Many consumers and purchasers tend to perceive evaluated products to be of better quality than those

that have not been examined. For example, products that receive high ratings from independent consumer organizations may sell much better than those that are either not rated highly or not evaluated at all.[5] Decisions about large-scale implementation of an IHC application will likely depend largely on assessments of outcome evaluations. That is, health plans and other large purchasers of IHC applications tend to be interested in products that have been evaluated and shown to effective or cost-effective for their organizations. Evaluated products also are likely to be perceived as more trustworthy.

2. *Higher profit margins and return on capital.* Consumers and other purchasers often are willing to pay more for an evaluated product that has been reviewed favorably. This may lead to greater investment value, such as market capitalization, for investors.
3. *Improved effectiveness, utility, reliability, and innovation.* By incorporating evaluation methods throughout the development and implementation process, developers can gain valuable feedback from users to inform product design and ensure a more attractive, effective, and user-friendly application. In addition, evaluation can encourage innovative application design by identifying promising approaches for further development.
4. *Greater acceptance by health professionals.* Many IHC applications involve the participation of health professionals. They generally respond well to, and are more accepting of, products that have undergone an evaluation in a peer-reviewed manner.
5. *Decreased potential liability for harm.* Developers who have evaluated their product thoroughly to minimize any associated health risks may be less likely to be found negligent if an individual claims the product resulted in some harm.
6. *Reduced likelihood of government regulation.* Unless products are routinely evaluated, it is likely that some potentially harmful programs will result in severe health consequences, and public calls for government regulation of the industry may result. Adoption of a voluntary standard for routine evaluation of applications by developers may avert harm and forestall resulting government intervention.
7. *Promotion of positive public image.* If harmful products are released, the public image of IHC developers and the industry could be tarnished. This may lead to substantial reductions in use of IHC.

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[5] There is limited scientific research on the impact that public release of evaluation results of goods and services has on subsequent sales, but anecdotal reports suggest that products rated highly by *Consumer Reports* tend to sell better and low-rated products decrease in sales (Shapiro, 1992; Kelly, 1994; Eldridge, 1997).

Psychosocial Theories and Models and Evaluation of IHC

The psychosocial theories and models summarized in Chapter III can be utilized in evaluations of IHC applications. For example, researchers have examined whether appropriate matching (tailoring) of psychosocial concepts to individuals influences behavior change and informed decisionmaking more than providing unmatched concepts (Curry et al., 1991; Velicer et al., 1993; Campbell et al., 1994; Skinner et al., 1994; Strecher et al., 1994; Brug et al., 1996, in press; Shiffman et al., 1997) or deliberately mismatched communications (Dijkstra et al., in press). These outcome evaluations provide information related to whether the overall approach was successful.

It should be possible to determine whether IHC applications are influencing targeted psychosocial concepts and whether these applications are moving individuals through the maps laid out by theory-builders. Assessing the concepts either before or as part of the IHC application, followed by post-treatment assessment of the same concepts, allows evaluators to examine changes in the concepts targeted by the application. For example, if perception of one's risk is viewed as an important factor in health-related behavior change, then it should be possible to determine whether the application is influencing this concept. In turn, it should be possible to determine whether changes in risk perception influence changes in the targeted behavior.

Many current psychosocial theories are sufficiently organized to hypothesize the relevance of a construct based on the specific state of the individual. For example, risk perception, in a number of models, would be more relevant to an individual not interested in changing a health-related behavior than to an individual ready to make the change. Other concepts, such as self-efficacy, become more relevant once the person is interested in making a change (Velicer et al., 1985; Bandura, 1986; Weinstein, 1988; Prochaska et al., 1992; Strecher and Rosenstock, 1998; Dijkstra et al., in press). Assessment of motivational stage has been an important method of framing a broad spectrum of behavior change interventions (Velicer et al., 1985; Prochaska et al., 1992). Evaluative efforts could, in turn, determine whether the individual moves through these stages of change as a result of the IHC application.

Standard evaluations of outcomes determine whether an application works. Evaluations that examine intermediate, psychosocial concepts linked with a conceptual framework of the IHC application determine why an intervention did or did not work. Both are important as more powerful, relevant applications are developed. Understanding how and when to measure intermediate psychosocial processes requires an understanding of the relevant theories and the psychometric properties of the concepts within these theories. For this reason, it is important that individuals with expertise in behavior change and decisionmaking theories become more involved at the earliest stages of IHC application development. Explicit development of conceptual frameworks guiding the content of the program may lead to stronger applications and improve the quality of evaluations for IHC applications.

Link Between Application Development and Evaluation

Evaluation of IHC is an ongoing process that begins during the product development cycle and continues for the life of the product. Given the highly dynamic state of IHC, development and accompanying evaluations would never really end because content will become outdated and new technology-based approaches and delivery methods will emerge. In addition, there is a role for evaluation even after an evaluated product has been in the marketplace for a period of time. As with drugs and medical devices, post-marketing surveillance data can alert developers and policymakers to potential harm associated with product use that may not have been detected in initial evaluations among limited study populations.

It is helpful for developers to understand the relationship between development and evaluation activities during the product development cycle. An inventory of potential application development and evaluation activities is presented in Table IV-1. At each stage of application development, from conceptualization and design to assessment and refinement, there is a series of evaluation activities that are relevant and should be considered. An array of evaluation methods and tools can be used to implement these evaluation activities. As illustrated by Table IV-1, there may be some overlap between development and evaluation activities.

Ideally, an evaluation plan should be formulated at the conception of an application. User needs and the objectives of the application should be clearly specified prior to implementation. Identifying intended effects helps define the outcomes of interest and the appropriate evaluation design to measure outcomes. Needs assessment is one of the initial stages of evaluation and the results of this analysis help determine product specifications. Evaluations during product development include component testing to ensure that all aspects of the system perform accurately and meet design specifications. Iterative usability testing to ensure that the product meets the needs of potential users with regard to usability and the facilitation of workflow or tasks is critical.

Experience has shown that several 1- to 2-hour sessions where individual learners are observed as they use an IHC application, and then are personally interviewed, can provide accurate usability feedback. Just four or five participants can provide sufficient information to complete a study of an application. Because of the small number of participants, this approach is more easily arranged than those with larger groups, and can be completed in one to three days depending on the facility and personnel available. If there is sufficient funding, IHC designers should utilize the services of professional usability testers. If funding is modest, designers may choose to conduct their own usability testing using portable usability lab equipment. When conducting one-on-one usability studies, it is very helpful to maintain a relaxed and informal atmosphere that encourages both negative and positive participant feedback. Without proper rapport, participants will likely be less open and may unintentionally invalidate the study. Developers should realize, however, that a usability lab may be much more of a controlled environment than the home. With experience, any developer can learn the skills necessary to conduct usability testing at the minimum level of formality required to obtain strong evidence that can be used to improve an application.

The next stage of evaluation is to measure outcomes during system use. At this stage, conducting a pilot evaluation to work out the implementation details of the evaluation and assessment tools is often helpful. Quite often, there are obvious misunderstandings of terms or unanticipated barriers that can be corrected before beginning the larger, more complete study. Because evaluation of IHC applications should be a continuous process, there is no “final” stage of evaluation. For many IHC applications, a long-term commitment to a process of updating and revision with ongoing quality-assurance evaluations is required.

Table IV-1. Key Development and Evaluation Activities in IHC Application Development

Stage	Key Development Activities	Key Evaluation Activities	Potential Evaluation Methods
Conceptualization and Design	• Describe the health issue/problem • Identify existing programs and gaps • Identify target audience(s) and needs • Identify program goals and objectives • Identify messages and content • Identify and collect relevant raw information and data • Tailor and develop content and data to fit needs • Identify resources • Develop business plan and marketing/dissemination/communication strategy • Draft product timetable • Identify media access among target audience(s) • Select specific media to utilize	*Formative evaluation* • Assess needs of audience(s) and whether needs are adequately addressed in design • Assess scientific literature • Assess relevance of completed evaluations of similar products • Develop evaluation plan • Develop and pretest communication strategies • Pretest content (messages and information) on target audience • Pretest prototypes on target audience(s) and revise design as needed • Assess and specify system requirements, features, and user interface specifications	• Case studies • Focus groups • Task analysis • Surveys • Interviews • Literature reviews • Simulations
Implementation	• Establish process measures	*Process evaluation* • Monitor the operational characteristics of the intervention • Assess security, accuracy, reliability, usability, response time • Assess user satisfaction and utilization patterns	• Simulations • Pilot tests • Focus groups • Protocol analysis • Interviews

			• Statistical process controls • Total quality management/ continuous quality improvement • Usability testing
Assessment and Refinement	• Implement evaluation of short- and long-term impact • Revise program based on evaluation and feedback	*Outcome evaluation* • Examine intervention's ability to achieve its intended effect and/or its cost-effectiveness • Analyze feedback and evaluation results • Share evaluation results and lessons learned with others	• Randomized controlled trials • Quasi-experimental trials • Surveys

Partially adapted from: National Cancer Institute. *Making Health Communication Programs Work.* Bethesda, MD: National Institutes of Health, US Department of Health and Human Services. NIH Publication no. 89-1493, April 1989.

Original version published in: Eng TR, Gustafson D, Henderson J, Jimison H, Patrick K, for the Science Panel on Interactive Communication and Health. Introduction to evaluation of interactive health communication applications. *Am J Prev Med* 1999;16:10-15.

Challenges of Evaluating IHC Applications

It would be misleading to suggest that high-quality evaluations of applications will be conducted if only developers would simply decide to do so. Indeed, there are several challenges to evaluation of IHC applications—some technical and some related to external forces—that will need to be addressed. High-quality evaluations will require careful planning and implementation, along with consideration of the following factors:

1. *The dynamic nature of IHC technologies and application content.* Regular updates to IHC applications are common because of the rapid changes in information and communication technologies and constant advances in biomedical and public health research that lead to new health information. The advent of software agents that automatically update content of Internet-based IHC applications is another challenge to evaluation. Therefore, evaluation methods must be able to monitor changing applications over time. This is in contrast to evaluation of static communication media such as books and journal articles. In addition, there is often a trade-off between accuracy and currency of information used in IHC applications because, over time, new health information typically becomes more refined and its relevancy better understood. For example, information appearing in IHC applications may not have been "vetted" to the extent that it is in textbooks and other more static media.
2. *The wide spectrum of applications and vehicles for dissemination.* The variety of methods for dissemination of IHC applications may influence program effectiveness and complicate assessments of utility. For example, because of privacy and confidentiality concerns, an application dealing with a sensitive health issue may be more widely and appropriately used if it is available anonymously through a public network rather than through a health plan's private network.
3. *The complex nature of IHC technologies.* It may be very difficult to accurately assess the relative effects of IHC program content, design, user interface, media selection, method of dissemination, and user-specific characteristics. The need to account for nonintervention-related environmental factors, including the myriad of other media influences that may influence health outcomes, further complicates evaluation design.
4. *Lack of practical approaches and tools.* Practical, evidence-based evaluation approaches and tools that are sufficiently flexible to evaluate heterogeneous applications over time, and can be used by stakeholders with varying evaluation skills and needs, are limited.

5. *Perceptions about evaluation.* Some developers believe that evaluation may delay product release and increase development costs, and that product marketing, rather than product evaluation results, is the key determinant of sales. Some investors may have a short time-horizon and discourage any potential delays in bringing a product to market. In addition, some developers perceive that purchasers are unwilling or hesitant to pay for product evaluations. These concerns are common among developers of technology-related products because the competitiveness of the field mandates special attention to time-to-market and development costs.
6. *Need to evaluate implementation strategy.* Because the implementation strategy of an application, in addition to the characteristics of the application itself, is likely to impact on its use and effectiveness, evaluators also need to consider implementation issues.

Evaluation Criteria

A number of organizations and individuals have published, and, in some cases, implemented criteria for evaluating the appropriateness or quality of health-related and other Web sites (Jadad and Gagliardi, 1998; Pealer and Dorman, 1997). Some of these criteria are the basis for tools used to produce a summary rating or grade to help potential users assess the site. There are literally dozens of criteria proposed in the literature (Kim et al., 1999), many of which are closely related.

In selecting and prioritizing criteria to use in evaluating IHC applications, developers and other evaluators often will consider many factors, including the objectives of application and the preferences and values of the evaluator and potential users.[6] After identifying relevant criteria, the relative weights assigned to each criterion may vary depending on the application. For example, for an application that provides information about clinical trials to the general public, accuracy and appropriateness of content may receive relatively heavy weighting. In contrast, evaluators of an application that focuses on enhancing peer support for a chronic health condition among a disabled population may choose to emphasize the usability of the program.

For general purposes, key criteria for evaluation that can be applied to most programs include (Henderson et al., 1999):

1. *Accuracy of content.* This includes a number of components, including currency and validity. Sometimes new and seemingly accurate information may not be validated under the scrutiny of time and broader experience. Ensuring the accuracy of the content is not always clear-

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[6] See Appendix E for a discussion of evaluation criteria from the user's perspective.

cut because there is a close relationship between accuracy and other attributes of information. For example, it is possible that information is accurate but still misleading in certain contexts. Wide variations in use of medical interventions have been linked to varying interpretations of the same evidence. Accuracy can be in the eye of the beholder. In addition, in some applications, the boundary between actual content and advertising may be blurred and identification of the source of the content may be difficult.

2. *Appropriateness of content.* This includes applicability and intelligibility to the user. Many applications are intended for use by only certain groups of people or only in specific situations. Developers need to be explicit in identifying appropriate audiences to ensure that the content is both applicable to such users and that the likely users can understand it.
3. *Usability.* This measures how easily a user can get the program to perform as intended. This is where quality interface design is critical. A flashy interface may be appealing to the senses, but actually make an application harder or more intimidating to use. Usability of any computer program, including IHC applications, is a combination of the following user-oriented characteristics (Schneiderman, 1997): 1) ease of learning, 2) high speed of user task performance, 3) low user error rate, 4) subjective user satisfaction, and 5) user retention over time. Hix and Hartson (1993) and Nielsen (1993) provide expert guidance to evaluating user interface issues, a process known as usability testing. The three major usability classifications are efficiency, user satisfaction, and effectiveness. Characteristics such as cost savings or minimizing training time fall under the classification of efficiency and are strong concerns for any organization making the investment in interactive learning. Ease-of-use, perceived benefit versus time invested, intuitiveness, and visual appeal are generally classified as user satisfaction. Immediate retention, retention over time, and transfer to actual job performance are categorized as effectiveness. Unfortunately, effectiveness is the least likely classification to be measured even though it is the primary intent of education and training in most contexts. Another component of usability is acceptability. Developers must be careful that the interface, or its elements, do not intimidate or antagonize users.
4. *Maintainability.* This is important because application content and design and likely users may shift over time, thus, requiring modifications to the program. A plan for who will implement changes, how the changes will be accomplished, and the resources required is necessary before implementation of the application.

5. *Bias.* There are many sources of bias, including origin of funding and personal biases due to background and training of developers and evaluators. It is imperative that developers and evaluators incorporate strategies to prevent or minimize bias. Sources of bias should be disclosed explicitly but they cannot be eliminated because the perception thereof is dependent on the individual user. Nevertheless, it is important to be sensitive to, and aware of, both potential and actual biases. For example, if a program incorporates an assumption that alternative medicine is good (or is bad), it can be both limiting (e.g., to whom it has sales appeal) and dangerous (e.g., in terms of liability to both developer and provider). Although conflicts of interest do not necessarily lead to bias, it is often nearly as important to avoid the appearance of bias as it is to avoid it in reality. Thus, it is incumbent upon developers and evaluators to avoid any potential conflicts of interest. When this is not possible, it is essential to use the most objective and bias-resistant criteria.
6. *Efficacy and effectiveness.* These are measures of the extent to which a program actually has its intended impact. For example, for applications that promote behavior change, does the program actually help people adopt the new behavior? For decision support applications, does the program provide adequate, reliable information that enables the user to make an informed decision? Does it result in decisions demonstrably more consistent with the patients' stated preferences? Technically, efficacy refers to a program's impact under controlled (experimental) environments, and effectiveness is the program's impact under real-world conditions. It is possible for a program to be efficacious in controlled trials but not be very effective when implemented under field conditions.

Standards of Evidence

Much of the controversy in the field of evaluation has to do with standards of evidence. An understanding of this concept is helpful in interpreting evaluation results. Two central concepts are the reliability and validity of the evaluation.

Reliability and Validity

Reliability can be seen as repeatability: If one asks the same question of the same people repeatedly, would he or she get the same answer? Poor reliability makes it much more difficult to measure the effect of an intervention. Thus, it is very important in evaluations to be certain that what one is asking is understood fully by those who are being asked, and that they can provide dependable or reliable answers.

The validity of evaluation findings can be viewed as the truthfulness of the findings. Do the measures really reflect what is intended to be measured? Are the findings correct, or are they an aberration? Are they meaningful in this context? There are two types of validity: internal and external. Internal validity is the validity of the findings within the study itself. External validity is the validity of applying the findings to other situations. External validity often is referred to as "generalizability." If the people who tested a program liked it, will everyone else who uses it have the same overall reaction? Can the results obtained with the study sample be generalized to other groups? Generalizability can be critically important because, in some situations, developers rely on the findings or results obtained by others. For example, if tailoring improves message impact in similar settings, it may be more appropriate for a developer simply to adopt a proven approach rather than to conduct additional evaluations.

Judging Effect: Statistical Significance and Effect Size

Many evaluators emphasize the statistical significance of outcome findings, and some may conduct statistical tests on a variety of outcomes hoping to find a statistically significant result. Although statistical significance is an important measure of intended effect, it can be over-emphasized. The key concepts underlying statistical significance are as follows: To what degree are we confident that the results did not occur by chance? Is there really a connection between use of the program and the outcomes? What are the chances that the outcomes really are due to the intervention, rather than due to chance and chance alone? The traditional metric of scientific studies is a p-value less than 0.05, which simply means that no more than 5 percent of the time, or 1 in 20 times, would one expect a given result to occur by chance. In other words, there is at least a 95 percent probability that the outcomes occurred because of the program rather than by chance. Reporting absolute probabilities often may be helpful. Statistical significance depends greatly on the size of the study sample (i.e., the number of participants in the evaluation). A larger sample size and/or a larger effect size both contribute to greater statistical significance.

When judging the usefulness of an IHC application, effect size often is a more important concern. Effect size is used to describe the magnitude of impact the intervention has on its users. For example, for a program that encourages diabetics to monitor their blood sugar more carefully, just how much more (or less) carefully do they do it after using the program? If an application is designed to decrease utilization of a service, to what extent do users of the program utilize that service less (or more) than people who did not use the program? While the statistical significance of results is important, it may be more meaningful to know how strongly it affected the users. Therefore, effect size should be considered along with statistical significance in evaluating outcomes.

What is a reasonable standard of evidence for IHC applications? Subjecting all IHC applications to randomized-controlled trials is neither practical nor appropriate. Although such trials produce the strongest evidence, they are not suitable for all interventions or for all stages of product development and dissemination. Developers face the challenge of balancing the need to conserve limited resources with protecting the safety of users and ensuring that the program is effective. One reasonable approach is to match the level of evaluation to the intended purposes of the application and the resources it consumes. That is, in the case of applications that have substantial potential risk or require a large investment, it seems appropriate to demand a higher level of evidence, such as an appropriately designed and implemented randomized-controlled trial. The level of confidence in the evidence of safety and efficacy for such interventions (e.g., shared decision support applications for serious illnesses) should be "beyond a reasonable doubt." However, for interventions that have minimal potential risk and require few resources (e.g., Web sites that provide general information from trusted and reliable sources), formative and process evaluations may be sufficient to provide a "preponderance of evidence" indicating that the application will be beneficial to users. In addition, evaluation methods, such as interviews and focus groups, often may provide important insights and understanding of how an application may benefit users as randomized-control trials.

Standardized Reporting of Evaluation Results

Prior to the Panel's work, there were no models for standardized reporting of evaluation results for IHC applications. As a first step toward promoting appropriate evaluation and disclosure about IHC applications, the Panel developed an "evaluation reporting template" (Appendix A) and a "disclosure statement" (Appendix B) to serve as a guide for reporting essential information and the results of any evaluations about a specific IHC application (Robinson et al., 1998).

The template is based on the rationale that all applications should undergo some level of evaluation, and that the results of such evaluations should be available to potential users and purchasers of the application. Disclosure of such information may enable potential users and purchasers and others to judge the appropriateness of a given IHC application for their needs and compare one application with another. The notion of disclosure of information about IHC applications is similar to the common practice of disclosing information about the use of a potential intervention or consumer product. Examples of this practice include health professionals informing patients about the risk and benefits of potential treatment options or experimental trials (Rodwin, 1989), and manufacturers disclosing product information (e.g., automobile specifications, nutritional content analyses) that may be critical to a potential buyer's decision.

In developing the template, the Panel identified a critical set of information that would help inform decisions about use and purchase and also would apply to essentially all IHC applications, regardless of the specific technologies or communication strategies employed or the goals of the program. Some developers may find addressing all the elements of the template to be somewhat overwhelming but not all IHC applications need to be evaluated in all of the categories specified in the template. To the contrary, evaluation targets should reflect the specific needs of the target audience and the objectives of the developer.

The Panel believes that all IHC stakeholders can benefit from a voluntary standard of reporting evaluation results. This template and its future versions can: 1) assist developers plan, conduct, and report the results of their evaluations; 2) help users determine which applications are most likely to benefit them given their particular needs; 3) assist clinicians in selecting relevant applications for their patients; and 4) help purchasers, investors, and policymakers focus on the most promising applications and strategies for investment and dissemination.

Will developers of IHC applications voluntarily disclose information about their products? As mentioned previously, there are several benefits to developers who conduct evaluations. With increased awareness among users and purchasers about the possibility of harmful effects or no effect from IHC applications, these groups will increasingly seek information about an application before using or purchasing it. If the current leaders in IHC development begin the process of public disclosure of information about their products, market forces may pressure other developers to follow.

Although version 1.0 of the template arose from an extensive multiyear development effort, additional refinement is necessary, and the template will need to be updated as it is used and the field evolves. As with all instruments of this type, deficiencies will be identified and improvements can be made as the template and disclosure statement are circulated to, and used by, wider audiences.

V

Major Issues for Key Stakeholders

The Panel has identified several stakeholder groups that need to participate in IHC application development, evaluation, and quality assurance activities if meaningful evolution and quality improvement of IHC is to occur. These include consumers (including patients, families, caregivers, and communities), IHC developers, purchasers and investors, health professionals, and policymakers, all of whom have related roles.[7] Developers of IHC applications are a vital link between the consumer and various sources of information and support. They also have ultimate control of evaluation and quality assurance aspects of these interventions, and are clearly influenced by the needs of the purchasers and users. Potential health care purchasers, including health plans and employers, determine whether IHC applications are implemented for their plan members or employees and directly influence the financial success of commercial developers. Investors determine which commercial applications receive funding to reach the marketplace. Health care and public health professionals often mediate the use of these applications with patients, and are involved in the development of IHC applications. Policymakers influence the climate in which stakeholders make decisions about the development, use, or purchase of IHC applications.

Understanding the various concerns, motivations, and potentially different perspectives of all stakeholders may be valuable in establishing collaborative

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[7] The term “purchaser” is used here to refer to purchasers of health services and products, such as health plans, other health care organizations, large employers, and government agencies.

efforts and in arriving at a consensus on appropriate directions and policy for IHC. In this chapter, the Panel outlines some of the major IHC-related issues among key stakeholders.

Developers

As mentioned previously, many types of developers create applications. Although their background and available resources for product development and evaluation may vary widely, they face similar obstacles in producing effective and useful programs (Jimison et al., 1999; Henderson et al., 1999). Many of these barriers have their origins in the competitive marketplace. The rapidly shifting nature of technology and the marketplace for IHC makes economic success difficult for many developers.

Balancing Science and the Realities of the Marketplace

How do developers balance their responsibility to use scientific principles in product development with the realities of the marketplace? IHC developers—commercial or nonprofit, large or small—are typically under tremendous pressure to deliver their products on time and within budget. Developers are pressed to produce high-quality applications in an extremely competitive environment with limited resources. This is the norm for the software industry. The emphasis on releasing products to the market as quickly as possible often results in applications that have fewer features than originally envisioned or ones that have not been fully tested and evaluated. The competitiveness of the market, from some developers' perspectives, precludes them from investing appropriate time and resources to fully evaluate a system before release.

Investing in Marketing Versus Evaluation

What is the appropriate balance between investing in marketing and evaluation activities? Some developers believe that aggressive marketing efforts, rather than positive evaluation results, ultimately drive sales and commercial success. In some larger companies and organizations, decisions about evaluation activities may be made by managers and executives, and developers may be frustrated by the need to convince these decisionmakers about the importance of evaluation.

Obtaining Funding for Development and Evaluation

How do developers get adequate resources for application development? Venture capitalists and large corporations may invest in commercial developers. Government or private foundation grants are often the primary sources for smaller developers. This is particularly true for developers who are part of nonprofit organizations. Competing for capital is of utmost concern for many developers. As a result, many are reluctant to collaborate or share their ideas with potential competitors. A list of potential resources for locating funding for IHC development is presented in Appendix C.

The scenario in Box V-1 illustrates some of the difficult issues that developers face when they try to balance time-to-market considerations with their responsibilities for quality assurance and evaluation.

Box V-1

A Developer's Dilemma

The PDM company was formed by the Jones brothers, Paul (a programmer), Bob (a business school professor), and Greg (a physician), in response to the news that their father had been diagnosed with prostate cancer. As their father informed each of them about his condition, he also expressed his confusion and doubt about what to do. Each brother commiserated with him about the difficulty of working through the available options for prostate cancer treatment. One evening not long afterwards, the brothers were having dinner together and talking about their father. They agreed that men like him needed a program to help sort through their options in a way that would help them make the best possible decisions during a difficult time. Collectively, they felt that their unique assemblage of talents gave them a special understanding of what was needed and how to do it. As a result, they created the PDM Company (for prostate decisionmaking) with a goal of creating (and selling) an interactive application that would help men decide about treatment options–thus making some money while meeting a real need.

With expert medical guidance recruited by the physician brother and decisionmaking expertise from the business school brother, the programmer began creating their flagship program. Due to major disagreements among the medical experts about which treatment options actually were most desirable, the project schedule started slipping. Meanwhile, Bob was holding focus groups to determine what men thought would be most useful and to get their reactions to mock-ups of the program. Enthused by the reactions of the men he spoke with, Bob began encouraging Paul to expedite development of the program. Greg was very concerned about the potential to lead men into the wrong decisions. He was worried about both legal liability and the moral/ethical issues of encouraging specific decisions, even inadvertently. Bob, an expert in marketing, explained how easy it is to influence decisions while providing seemingly neutral information. Paul suggested an extensive program evaluation to make sure the program actually helped men make the right decisions. They all agreed this sounded like a good idea.

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Paul was coordinating the production of multimedia assets (graphics, audio files, and video) as well as programming. The video subcontractor kept delaying production and Paul could not finish the programming without the assets. Then, a major new microcomputer operating system (OS) version was announced and Paul realized his program would need to be changed if it was to run under the new OS. Each delay meant more days and weeks of effort, rent, subcontracts running over budget, and other expenses. Money was becoming a real worry. Finally, Paul announced that a pre-beta version was available for testing. Bob tried to run it on his office computer but he did not have the right multimedia software installed. He gave the program to others but all of them ran into some type of bug or installation glitch. Paul tried to create new versions for each problem that was encountered. Bob began to worry about just what types of computers could run the program. Was the installed base a big enough market? Maybe they should simplify the program so that it would run on more computers or make it a Web-based application? Paul was beginning to feel stressed out. Greg kept asking about the big delay.

Not much later, Paul produced a "final candidate" program and they began pilot testing with five men recently diagnosed with prostate cancer. Despite some glitches, the program worked pretty well and the men generally liked it. They felt it definitely was useful and had helped them make good treatment decisions. Greg was called in and the three Jones brothers began discussing an evaluation that would include enough men to have a statistically meaningful sample and would use a randomized control trial design. Greg and Paul agreed that anything less would not really tell them whether the program worked well or lead to any bad decisions. It would take about six months, but it was all going to be worth the effort. The euphoria of being so close to completion lasted three days. Then, Bob was at a conference where he overheard two men talking about the prostate decisionmaking program they had recently seen demonstrated. "Very slick," said one man. "Yes, they've got a winner I'd guess," added the other. "Do you really think they can ship it within the next three months like they claimed?" asked the first. "I think so," was the reply. Bob ran to a phone and called Paul. To his surprise, Greg answered and immediately interrupted his brother to announce that Paul had completed the "final" program. "Great news!" he added. "We're ready to begin the randomized clinical trial. My friends, the ones with that huge urology practice I told you about, have agreed to start referring patients Monday." Bob brusquely replied, "Forget the trial, we've got to ship right away or we'll get scooped! I just heard about another program coming out." What ensued was a bitter argument about whether or not they had sufficient data to begin shipping the program.

"We can get data from actual users," said Bob. "Without random assignment, we cannot be sure what that kind of data would mean," said Greg. Paul added, "I don't want to do any harm but I don't really see how we could." Greg explained how leading a man into the wrong decision could mean an unnecessary end to his sex life, on top of urinary incontinence. "Think about no more intercourse and being incontinent the rest of your life," Greg said. "But we probably have been more careful about creating a balanced program than our competitors. If we don't go to market now we may not make anything out of this!" Bob said with emotion. "I don't think we should market it unless we have data to back up its efficacy and safety," said Greg. "But that's what the pilot data says, isn't it?" asked Paul. "It's not conclusive, there were only five men," said Greg. "Yes, but it's the best we can do for now," added Bob. "We can run the trial while we start marketing, can't we?" said Paul. Silence followed as each brother thought about the choices and implications. Paul spoke, "Well, what about it? We could start the trial as planned and Bob can start the marketing plan. By the time we ship a significant number, we should have preliminary data from enough patients to see if there are any major problems. We will keep analyzing the trial data as they come in and if we see any problems we yank the program and fix whatever has come up." Greg shook his head, "If we cause a problem I'd have a hard time living with it. First we test, then we ship." Bob looked glum. He said, "You do understand we could lose everything we've put into this?" Greg sighed and said softly, "Yes, I do."

The next three months were tense ones for PDM. After enrolling the first 20 men, they discovered that about half of the users were missing a critical section of the program due to a confusing interface element. The experienced computer users understood the interface metaphor Paul had programmed, but the others missed it. It was a serious problem, but easily fixed. Moreover, their competitor did release a comparable program. They heard about it while reading an industry newsletter. There was a review of their competitor's program by a physician. Their dismay turned to glee as they read the review. The gist of the review was that the program had offered terrible advice, "evidently based on faulty algorithms," concluded the reviewer. The reviewer strongly suggested that the program be pulled off the market before the developers (and any clinics making it available to patients) faced lawsuits. The brothers carefully reviewed their own program to make sure it did not have similar

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problems. Once the randomized clinical trial had produced enough data, Greg gave a peer-refereed presentation of the scientific data at a national meeting. A medical director for a very large HMO approached Greg after the talk and asked if he was prepared to negotiate for "the purchase of a rather large number of copies to be used across all of their sites."

Key Considerations

- The first guiding principle must be: "Do no harm."
- Two key ingredients are content expertise and accurate knowledge of the target population (i.e., their desires, capabilities, and needs). Both are necessary for optimal program development.
- Key design decisions (e.g., specific behavioral goals, target platform, structure) must be made carefully—and early in the development process—to avoid wasted efforts and costly delays.
- Adequate testing of the programming and the content are critically important—both to ensure efficacy and to avoid liability.
- Premature marketing can result in problems worse than reduced market share.
- Good efficacy data can be an important sales factor.

Health Professionals

Health care and public health professionals have a vested interest in offering patients and consumers reliable and useful health information because providing access to quality health information has the potential to both improve the quality of health care and lower costs (Jimison et al., 1999). The challenge for health professionals and purchasers is to identify systems that are effective and warrant further investment of resources, time, and integration into clinical practice and preventive programs. In a shifting paradigm where patients may have just as much or more access to the latest health information, clinicians and other health and safety professionals will be challenged to find ways to become involved in the health information-seeking process and be able to add value to this process.

Employee health and safety directors, occupational health nurses, industrial hygienists, and others in workplace settings, are examples of health and safety professionals who could benefit from IHC applications. The recommendations for reducing the risks associated with workplace hazards often require the development and implementation of complex engineering and administrative controls—measures which require expertise and often need to be tailored to individual work settings. As a result, controlling occupational health and safety hazards can be costly and time-consuming for employers and workplace health and safety professionals. IHC has the potential to reduce costs and occupational risks by alerting health and safety professionals about newly identified hazards, and by providing accessible, comprehensive, and tailored information for developing and implementing controls.

Impact on Role of the Clinician

How will IHC impact on the traditional role of clinicians? How should IHC applications be integrated into clinical practice? It is unclear exactly how IHC will change the role of clinicians but it is likely to be a gradual rather than an abrupt process. As discussed previously, some health care professionals view IHC as a threat to their traditional relationship with patients. Others become discouraged at the thought of managing patients who are avid health information seekers given the confines of a 15-minute appointment. These concerns are somewhat magnified for some clinicians because they are occurring in the context of the growth of managed care. Regardless of whether their practice setting supports use of IHC, clinicians can make use of applications to improve patient care. For example, referring patients to quality Web sites for additional information or to well-regarded online support groups for peer support may help supplement the information and support provided during an office visit.

A related concern for clinicians is whether they will be reimbursed for their activities as information intermediaries as described in the next chapter. In many cases, administrators rather than individual clinicians ultimately make decisions about integrating IHC into clinical practice, particularly if they involve the purchase of hardware or software. Administrators, therefore, have a key role in successful implementation efforts.

Development of New Skills and Training

A 1997 survey among a nationally representative sample of 1,905 physicians showed that 42 percent use a computer for personal or professional practice purposes (Trotto, 1998). It is clear that as the roles of health professionals in the context of IHC evolve, additional training in new areas of responsibility will be required. These areas may include both technology-related skills (e.g., computer use, information searching and information evaluation skills) and communication-related skills (e.g., facilitating shared decisionmaking, interfacing with proactive information-savvy patients). Such training will need to be available during both health professional student and post-graduate training. In addition, IHC-related technology is rapidly becoming an essential tool for educating health professionals.

The scenario in Box V-2 illustrates several issues that may challenge clinicians in integrating IHC applications into their practice.

Box V-2
The Proactive Health Care Professional

Dr. Emily Chen is a senior physician with more than 20 years of experience in a large oncology group practice. During the last year or so, the clinicians in the practice have noticed a dramatic increase in the number of people who have been coming in with realms of printouts from Medline searches and other online resources. The clinical staff have been overwhelmed by these patients because much clinician time is required to address all their questions and concerns. Some of the clinicians also believe that most of the time spent with these patients is spent correcting inaccurate information or explaining why the information is not relevant to the patient's situation. As a result, these clinicians have been discouraging their patients from using online health resources. In addition, because the practice receives a fixed pre-negotiated reimbursement rate from the insurance company for most services regardless of the actual time involved, the practice administrator has strongly encouraged time limitations on many types of visits.

Dr. Chen has been reluctant to accommodate the more information-savvy patients in the practice and will sometimes only brusquely answer these patients' questions. Then, one day, a long-time patient of Dr. Chen's abruptly announces that, while he respects the quality of clinical care at the practice, his information and support needs are not being met. He is switching to a new practice across town because they not only answer all his questions, but they actually encourage him to conduct online research about his illness. In fact, this practice encourages him to e-mail the clinic staff with any questions he might have at any time. Asking around, Dr. Chen finds out that several other clinicians in the practice have had similar experiences recently. Concerned, Dr. Chen asks the practice's accountant to review the clinic logs. She finds out that there has been a significant drop in the number of new patients coming into the practice during the last year, and an alarming number of long-time patients have elected to leave the practice.

At their next meeting, the practice management team decides to conduct a survey to assess the information and support needs of patients.

The team learns that an overwhelming number of patients are dissatisfied with the information and support they receive from their clinician. It becomes clear to the team that the policy of not fully supporting patients who use the Internet to access health information and support is shortsighted and potentially ill-fated. Using the survey results, the team sets out to develop a comprehensive "patient information support" policy with input from an IT consulting company.

The team decides that the new policy would revolve around a proactive and comprehensive approach to managing patient information and support needs. Their goal is that all patients will be fully supported in seeking information and support, and fully satisfied with their clinical encounters.

The management team quickly realizes that, although most of the office staff have used personal computers, only a few of them have experience in searching for health information on the Internet. They hire a local medical librarian to hold a series of in-service training sessions on locating and evaluating health information on the Internet. The librarian also identifies several well-respected online cancer support groups that the clinicians start to use to get a sense of what questions and concerns are circulating among cancer patients and caregivers. The nurses, technicians, and other office staff are included in these training sessions because they will assume much of the responsibility for supporting patient information and support needs under the new policy.

A subgroup of the team is tasked with building the Web site for the practice. They start by locating and conducting reviews of relevant, health-information Web sites. This group carefully evaluates these Web sites using standardized evaluation criteria and creates links to sites that seem to be of highest quality and relevance to the practice's patient population. Sites that inform and guide cancer patients to appropriate clinical trials of new therapies are highlighted. They also contract with a regional cancer center to use some of their online content and adapt it to their patient population. To complement the health-information resources on their site, they purchase licenses for several risk-assessment and clinical decision-support tools from a university group after examining several peer-reviewed research articles documenting the effectiveness of these tools. In addition, during the course of the next few months, each clinician submits several "frequently asked questions" from patients and the answers are posted on the practice's Web site. All of the clinicians are now available by e-mail to handle nonemergency questions. Patients

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really like this because they no longer feel that they have to think of all their questions during their visits, and many have been reluctant to call their clinician for nonurgent questions.

The team also wants to make sure that all patients have some access to their Web site. On a trial basis, several interactive kiosks are installed in the practice waiting room. An "information assistant" is available to show patients how to use the system. New patients are instructed to use the kiosks to provide a detailed medical history so that the clinicians can focus on their responses rather than administering the history during their visit. Because the kiosks are linked to the Internet, patients also can access the online resources on the practice Web site while they wait. The office finds that the kiosks are well received, and that they actually free up time that the clinicians would have otherwise spent interviewing the patients and explaining basic concepts about cancer.

Several months after implementing their new "patient information support" policy, the team implements structured and open-ended surveys of patients to get their feedback on the new approach. They find that most patients are satisfied with the information and support they receive through the practice. They use the survey data to further refine their quality improvement initiatives. Dr. Chen and the other clinicians also have the following observations: 1) most patients seem to be well informed about their illnesses and their questions during visits are better focused; 2) many patients have become active participants in their care and seem to be more satisfied with their care; and 3) the number of patients in the practice has increased.

Key Considerations

- Clinicians have important roles in helping patients locate, assess, and interpret health information.
- Many health professionals will need training and skills-building in health information technology to adequately address the information and support needs of their patients.
- A proactive and comprehensive approach to addressing patient information and supporting needs can help improve patient satisfaction.
- Encouraging patients to use online resources does not necessarily increase the amount of time that clinicians have to spend with patients during visits.

Purchasers

Currently, the major purchasers of IHC applications are health plans, other health care organizations, and large employers. Emerging purchasers include government agencies, schools, and voluntary health organizations. Direct-to-consumer applications are becoming increasingly common. Health plans may be primarily interested in the potential of IHC to promote healthy behaviors and manage demand for services. Many employers consider purchasing an IHC application to help decrease health care insurance premiums and to reduce losses in worker productivity due to illness. Ultimately, both types of purchasers want to improve satisfaction among members or employees and lower health care costs. After purchasers make a purchasing decision, they then have responsibility for implementation and evaluation of the selected product. A checklist of evaluation-related questions for potential purchasers is presented in Appendix D.

Selecting and Evaluating Applications

How should purchasers compare competing products and what outcomes should they consider besides price? Major outcomes of interest to most purchasers include cost (i.e., all expenditures potentially influenced by the use of the system) and quality, including clinician and patient satisfaction, increased knowledge and healthy behaviors, improved health status outcomes, process control, improved access to and more appropriate utilization of health care services, and concordance between utilization and expressed preferences (Jimison et al., 1999). One outcome of importance to health plans is improved market growth with the use of IHC applications that may increase client satisfaction, retention, and new enrollments. Cost-savings may result from applications that facilitate disease management, self-care, and self-triage. Purchasers should keep in mind, however, that many individuals are much more interested in outcomes that reflect improvements in health, service, convenience, social support, and general ease of use, rather than cost-effectiveness and improved market share. Therefore, the former types of outcomes should also be important criteria for purchasers.

Strength of evidence is also important to consider when examining evaluation results (Robinson et al., 1998). The results should show internal validity (this is higher with randomized controlled trials, lower with observational studies), statistical significance (higher with larger samples and/or larger effect size), and clinical or system significance (sufficiently large effect). In addition, purchasers may wish to consider how applicable evaluation results are to their own circumstances and population. For example, in the case of a health plan, comparison of its patient demographics and organizational characteristics in terms of culture, incentives, and willingness to change or adapt, may shed light on whether evaluation findings are “generalizable” to their circumstances. As with all interventions, it is important to document whether the reported effect of a system is actually obtained in routine use among the purchaser's population.

Supporting Evaluation of IHC

From the purchaser perspective, the importance of supporting the evaluation of IHC applications is based on both quality-of-care and business criteria. Evaluation information can be used to identify more effective products, and the quality of health care will be improved if patients are using more effective systems for their health care decisionmaking. Without purchaser demand for evidence, there is little incentive for developers to evaluate their systems and evaluation information on competing IHC applications would be limited. Some purchasers, however, may not be concerned about demanding health status outcome evaluations because they are more interested in providing IHC applications as a marketing mechanism or as a means for improving member or employee satisfaction rather than in the actual impact of the product on health status. Appropriate evaluation results, however, would provide information about user satisfaction rates that could predict satisfaction in the purchaser's population.

Developing and Implementing IHC

What types of applications are most appropriate for members and employees? In considering whether to implement IHC in a health care organization, administrators will be concerned about several major issues. First and foremost may be whether IHC can address the needs of their members or employees. Addressing this question requires information about the population's health information and support needs, and an understanding of realistic outcomes of the application. Another major consideration is whether implementing a technology-mediated application adds real value compared with a more traditional method of providing information and support. Administrators also need to determine how to relate the IHC application to clinical information systems and to care delivery. Another important issue they face is whether to purchase external systems or develop applications in-house.

The scenario in Box V-3 describes several major issues related to how health care organizations may approach the implementation of IHC applications into their organization.

Box V-3
Implementing IHC in a Health Plan

Janice Rodriguez, an accomplished project manager, has just been recruited from an interactive health software company to be the regional chief information officer for a large progressive health plan with several facilities in the area. The CEO of the health plan wants the organization to be on the “cutting-edge” of using IHC applications to improve member health and to reduce costs of delivering care.

Eager to please, Janice embarks on an ambitious plan to eventually implement a comprehensive suite of Web-based applications to provide seamless health information and support for members, allow electronic member transactions, provide clinical decision support for members and clinicians, and facilitate electronic communication between clinicians and members. For the first phase of her plan, she focuses on selecting and implementing a shared decision-support application for members and clinicians.

Janice ponders whether to outsource the development of the application or to do it in-house. After an assessment of her department’s resources and an environmental scan of available applications, she decides on the former option. She surmises that, with a pilot project, it is better to minimize uncertainty. The health plan’s IT department has some expertise in general Web site development, but they are unfamiliar with decision-support applications. If she outsources to a company with an established product, she is assured of prompt delivery and can more easily predict costs. In addition, she is worried about potential liability issues. Relying on an established and rigorously evaluated application, she concludes, may help in that regard.

She sends out notice of what she is looking for to her former company and a few other contacts. Within a week, Janice is deluged with calls from more than a dozen companies that want to sell their product. Each of them claims that their product is of high quality and very effective.

Janice understands that she needs to base her decision on more than surface appeal or which salesperson can do a better presentation, because her boss is looking for bottom-line benefits to the health plan, such as increased member satisfaction and retention. She promptly assembles a team of people from the IT and clinical research departments with experience in evaluation. They review the literature on evaluation of IHC,

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talk to colleagues in other plans, and brainstorm, coming up with a list of questions for themselves and prospective vendors. The questions include: What are reasonable objectives for such an application within the context of the organization? Was the application evaluated with regards to these objectives, and what were the results? Has it been shown to be cost-effective? Is the product flexible and adaptable to the plans changing needs?

After reviewing additional information from the vendors, the team decides to purchase a hundred licenses of the application from a company that presented very convincing data on effectiveness which was published in a respected scientific journal. Janice and the team make plans to deploy the application in the primary care department in one of the plan's facilities because their medical director happens to be a "techie" and is very enthusiastic about the program. Things look positive; the application runs well with their existing clinical information system, the training session is well attended, and several of the primary care staff say that they are impressed with the technology.

Janice and her team check in weekly to see how things are going. After a month, only a small proportion of the clinicians has used the application with their patients. Janice interviews the staff. "I don't want to support using something that may eventually replace me," says one physician. "I like the program but I don't have time to use it during my appointments…I am also afraid that it will actually increase the amount of time I have to spend with some patients," says another. Yet a third comments, "It's too much of a hassle for me to use it because it crashes my personal scheduler program when I do. When I ask our IT administrator to help, he says he will not support it because he is too busy troubleshooting the clinical information system that the plan just purchased last year."

Janice's team realizes that they have formidable implementation problems on their hands, so they start again from square one, and recruit more troops. They fan out, interview additional stakeholders, hold extensive "town meetings," and form a plan-wide implementation team.

The team is divided into a number of smaller groups that are dedicated to a specific aspect of the implementation process. The development team takes responsibility for assessing the value of available applications, rating them according to compatibility with the health plan, and modifying and designing interfaces to reflect the organizational culture. The implementation working group will oversee the process of defining constituencies and determining how best to represent their needs in the dissemination process. The operations working group considers how the application will be merged with existing clinical care, how quality will be assessed, and how the application will be maintained. The evaluation group defines how the impact of the program will be determined, designs usability testing protocols, analyzes potential return on the investment, and determines how study results will be disseminated. The technology working group hammers out the "nuts and bolts" of the installation and designs the architecture to support the smooth operation of the application. Finally, a planning working group is formed to examine future opportunities and directions for new applications and development.

Meanwhile, a communication plan is set into action so that support for the program can be gathered from the stakeholders and opinion leaders throughout the organization. Key decisionmakers are identified to ensure continued financial support; they are encouraged to join the working groups and inject their concerns into the development process. Clinical staff members from all the facilities are asked to visit and report on changes in medical care and health plan policies. In addition, organization leaders continually address the working groups to inform them of organizational changes so that the applications are consistent with organizational goals.

Finally, the working groups meet every few months with their customers, including members of the health plan, clinical staff, and plan administrators. They define and refine the dissemination process, provide feedback on the success of the program, and brainstorm on future options for added technology.

A year later, a survey shows that 70 percent of members who have used the decision-support application are highly satisfied with their experience and believe that it not only helped them make a better decision, but also improved their relationship with their health care provider. A similar survey among providers shows that more than half have already adapted the application into their routine practice and believe that it improves the quality-of-care they deliver.

Key Considerations

- Health care organizations and other potential purchasers should carefully assess their internal capabilities for application development and maintenance before attempting to develop their own applications.

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- Purchasing decisions require careful consideration of the objectives for the application and evidence of application effectiveness.
- Substantial attention to, and planning of, the implementation process are critical. The process should be consistent with the organization's structure and culture, and address institutional barriers.
- Continuous evaluation and quality improvement are essential.
- Successful implementation is a team process; involvement of, and communication with, all stakeholders are necessary.

Consumers

Consumers, perhaps more than any other stakeholder group, vary in terms of their ability and experience in evaluating applications, and, thus, may be the most "vulnerable" stakeholder group. This is because a "consumer" may be a scientist or health professional by training, someone trained in a different field, or someone who has no formal education. Therefore, of all the stakeholders, consumers are probably at greatest risk of potential harm and need to be cautious because of the general lack of disclosure of information about developers and sponsors of IHC applications. Many applications are currently being used with no or limited guidance from a health professional. Most consumers are concerned about being able to select and use the best applications for their needs and require guidance and tools for doing so (Gustafson, Robinson et al., 1999). A "consumer's guide" for interpreting evaluation results reported by developers is presented in Appendix E.

Selecting Applications for Use

How do users select the most appropriate applications? Even if consumers recognize the potential for harm and wish to evaluate applications before use, will they be able to? The growing array of applications available makes the selection process extremely daunting. If independent evaluations of products are available, and they are presented in consumer-friendly terms, consumers would be better able to make informed selections of applications for their use. In many cases, however, no evaluations of specific products will be available, and the consumer will need to independently judge the quality of the application.

Consumers need to consider more than just the quality or accuracy of the information or content. Some products may make users feel anxious or overly confident, or may affect the trust they have in people important to them. What kind of emotional support does the product offer? Did it actually help them? For example, a program that offers only information and no social support may be less likely to promote behavior change or enhance coping with a disease (Brennan et al., 1995; Gustafson, Hawkins et al., 1999). Moreover, because different consumers learn in different ways, potential users need to consider which style of learning works best for them. Two applications that have identical information but different presentation styles may have very different effects on the same person. In essence, consumers may consider developing their own evaluation framework that includes consideration of content quality and outcomes related to personal coping and self-confidence in decisionmaking. Tools will be needed to assist consumers on how to be an educated consumer and implement an evaluation framework.

Building Skills to Use IHC Applications

What skills and training do consumers need to use IHC applications? Because of the newness of IHC, relatively few consumers have the skills needed to take full advantage of applications. In some cases, skills must be acquired under circumstances of high stress, such as in the case where an individual has just been diagnosed with a life-threatening illness. Unless application design takes into account the diversity of potential users (e.g., educational/computer skills level, disabilities), many resources will be unusable. Allowing users to provide feedback to developers is important to improving usability. In addition, enabling users to share their experiences with others may help them use applications more effectively.

The scenario in Box V-4 illustrates several important issues faced by consumers in selecting and evaluating appropriate IHC applications.

Box V-4
A Consumer's Experience with IHC Applications

Mary Smith returned home from the hospital with her week-old twins, a girl and a boy. Like many first-time mothers, Mary was both enchanted and overwhelmed with the challenges of her new family. The practical advice offered during the childbirth preparation classes seemed to escape her awareness at the very moment that questions about nursing the babies entered her mind. Her questions seemed too minor and insignificant to warrant a call to the nurse midwife. However, she remained worried, and a bit unsure about many of the day-to-day rituals of mothering twins. Encouraged by her partner, Mary decided to use some of the health information resources available on the Internet. During one

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of her first trips away from home, Mary stopped at the public library to use their Internet computer.

First Time: Finding Resources

Mary began looking for health information at her hospital's Web site. She brought along the address for the hospital's Web site, which she had found in her discharge instructions. Mary typed the address into the browser, and soon pages appeared on the computer screen presenting information by her hospital. Most of the information addressed logistics such as how to get to the hospital or where to park; however, several sets of keywords suggested that specific clinical advice might be available. Selecting the phrase "Help for New Parents" led Mary to discover a series of pages with helpful hints and explanations about taking care of infants.

One page described common sleep patterns for newborns, noting that smaller babies had more sleep difficulties than larger babies. This information confirmed Mary's experience with her five-pound twins, neither of whom slept more than three hours at a time. Mary read with eagerness the suggestions regarding how to establish successful sleep routines with small infants. Another page addressed bathing infants. Mary was able to view a short movie demonstrating how to hold small infants while bathing them. She learned that many soaps caused skin irritation in newborns, and reviewed a list of recommended bathing products.

None of the material presented on the hospital's Web site specifically addressed the needs of twins. Mary noticed the message "Search For Other Resources" just as she needed to leave the library to return home. She made a note to come back and check the new information.

Second Time: Follow-up and Exploration

One week later Mary returned to the library. By this time, she had begun to feel a bit more confident feeding and bathing the babies, but had found herself becoming increasingly weepy and sad over very small events. The babies seemed to be nursing successfully, but she continued to worry about her ability to feed them. Mary launched another session to her hospital's Web site.

Mary located the appropriate section within the hospital's Web site and looked through the listing until she found the message "Search For Other Resources." At this point Mary initiated a search. In response to a question requesting her topic, Mary typed in the words "newborn twins."

She received a list of 27 different Web sites, all denoting “twins” somewhere in the title of the pages. She began reviewing the pages one at a time.

A commercial baby food company presented the first page that Mary discovered. Included on this page were pointers to descriptions about various formula preparations and strategies for promoting health nutrition. Pretty colors and pleasing pictures of well-nourished babies made the page seem interesting; however, with her commitment to breast-feeding, Mary determined that the content on the page was not relevant to her current situation.

A second page led Mary to the Web site developed and supported by a national voluntary society, Parents of Twins. This page differed from the ones Mary had already viewed. In addition to the usual helpful reference materials, this page had a public bulletin board area where interested persons could post or read messages. Mary focused her attention here.

Mary discovered several hundred messages with topics ranging from “Twins—double trouble” to “Help—where can I find cheap diapers.” As Mary reviewed the messages, she noticed that parents of twins posted most of the messages. Many messages offered humorous or unnerving stories about child care experiences. Some posed specific questions, such as “Has anyone tried to nurse both babies at the same time?” to which other participants offered suggestions or advice. Occasionally a user identified himself or herself as a health care professional; their comments seemed different from those posted by the parents, offering clinical descriptions or recommendations to consult with clinical care providers.

Mary observed that the quality of advice in the postings ranged from very believable to almost ludicrous. Some postings clearly were advertisements in disguise, suggesting that a specific product may help with a given problem. Others offered helpful strategies, such as how to use pillows to position the babies comfortably during feedings. Occasionally a poster would direct readers to additional Web sites, which Mary herself sometimes subsequently viewed.

Mary noticed that a small set of individuals seemed to do most of the posting. Five or six users seemed to post several times a week, sometimes addressing their messages directly to other individuals or to the group as a whole. Phrases such as “Twin Moms Unite” or “Parents in the Know” created a sense of community that Mary knew she would

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like to join. Since no funds were needed to use the computer or to participate in the conversations in the bulletin board area, Mary resolved to return when she could and partake in this shared experience of parenting twins.

Maintenance: Linking IHC With Professional Care Services

When the twins were 4-weeks-old, Mary returned to the midwife for her post-partum checkup. In the conversation about her emerging role as mother, Mary described for the midwife the assistance and peer support she had discovered on the Web. Mary talked about the range of helpful (and sometimes unhelpful) advice provided by fellow users, and about the different Web sites that addressed child-care and parenting. Her midwife listened attentively, expressing support for Mary's abilities to seek out and interpret health-related information for herself. She reviewed Mary's strategies for determining the quality and relevance of the health information provided and identified some additional Web sites that she already reviewed and believed Mary would find helpful.

Key Considerations

- IHC applications are an important resource for consumers and public access to these resources is critical.
- Consumers need to be critical of the quality and relevance of online health information and support.
- The use of IHC applications can be more effective when their use is linked with regular care from a health professional.

Policymakers

Policymakers, both in the public and private sectors, determine the nature of the environment in which IHC development and implementation occur (Patrick et al., 1999). IHC policymakers in the private sector typically include executives of health care organizations and large corporations, and they are driven by their primary responsibility to ensure the financial viability of their organization. Their purchasing and investment decisions essentially determine the commercial viability and development of specific types of applications. Policymakers in the public sector, especially legislators and regulators, have decisionmaking power over the general field of IHC, and have to ensure that their decisions are consistent with the interests of their constituents and the general public. Both types of policymakers help determine the role of IHC in the overall mix of public and private investment in individual and community health, in disease prevention, and in health care and rehabilitation. Ultimately, policymakers are concerned with the impact that IHC applications may have on the structure, process, and outcomes of health and health care. Understanding how IHC applications relate to, enhance, and/or potentially detract from other determinants of individual and community health is important in developing policy. Major policy issues related to IHC are reviewed in the next chapter.

Promoting Quality and Access

How do policymakers promote quality and ensure safety of IHC while not hindering innovation and use? Policymakers will need to weigh the role of voluntary standards and self-regulation versus government regulation, and decide if or when it is appropriate to intervene or regulate. In some cases, such as in the case of fraudulent online marketing of health care products, Federal agencies such as the Federal Trade Commission have taken some action (FTC, 1997). Policymakers may consider implementing appropriate incentives to promote voluntary adoption of quality goals.

How do policymakers ensure that all populations have access to IHC? Some policymakers are increasingly concerned that the growing reliance on technology in health care and public health may leave the most needy populations without access to health information and support (Eng et al., 1998). The debate about who should pay to enhance access to telecommunication services is being played out in the context of the universal service provisions of the Telecommunications Act of 1996 (FCC, 1998). In addition, there are concerns about how applications that address issues of relatively small populations ("orphan" issues) can be supported if they do not have commercial value.

The scenario in Box V-5 outlines some critical issues that policymakers must deal with in developing and implementing IHC applications that contain personal health information.

Box V-5

A Policymaker's Dilemma

A county with a population of 2.5 million and a handful of dominant health care providers is working to develop a community-wide immunization registry for all children and youth under the age of 21. The vision is to have "anytime, anywhere" instant availability of information on the immunization status of the target population. The rationale for this is that having such information available at the time of either medical office vis-

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its or school and college health immunization initiatives, will reduce the likelihood that these individuals will "fall through the cracks" and remain un- or under-immunized against important and sometimes deadly diseases such as measles, rubella, and hepatitis B.

More than two years ago, the county director of public health convened leaders from each of the major health care providers, the council of community clinics (the members of which serve most of the uninsured), three major employers who, combined, provide approximately 60 percent of the county's jobs, and expert faculty from the local schools of public health and medicine. With support from staff of the health department, they have been meeting monthly to discuss ways in which the immunization registry can be built. Many of the technical problems that existed several years ago when the idea of a registry first surfaced are now more tractable in the face of growing acceptance of Internet-based technologies. These include problems such as interfacing disparate databases, sufficient connectivity between health care providers and the health department, acceptance of common definitions and language to use for procedures, and methods for secure and reliable transmission of information via the Internet, including safe storage behind adequate "firewalls."

However, in recent meetings, the group has become bogged down over three issues. First, while there is a desire to fully engage consumers in the process of helping to keep immunization data on their children up to date, there is worry over whether public access to even part of the registry might be put to unintended purposes (e.g., separated parents contesting custody of a child might use the registry to locate one another). Second, the general issue of making available personal medical information outside the confines of traditional health care settings is beginning to be the subject of call-in talk shows in the community. One county supervisor is particularly entrenched in his views about "big government" and how the potential for misuse exists in any governmental collection of information about individuals. Finally, there is concern about the accuracy and general quality of the information to be contained in the registry. The health care providers readily admit that when they perform audits on their own internal data sets for immunization information, they find errors and problems. This is in spite of substantial efforts on their part to maintain the currency and quality of this information.

What role can the local health department play to help this group move beyond these problems and create a functional immunization registry?

What liability issues are raised by the first concern? How can these issues be mitigated? Can the trade-offs between concerns about how access will be used and the need to engage consumers fully in helping the registry stay current be made to come out in favor of consumer involvement?

As for the second concern, how can the group move to community acceptance of the functions served by the registry? Is it acceptable to characterize the registry as similar in kind to other public health data functions and thus invoke the public health department authority and responsibility? If the county does not assume this responsibility what sort of entity could be developed to operate the registry that might reassure those concerned about "big brother?" What safeguards can and should the data communication and storage technology partners provide to assure stakeholders that data will be secure?

Finally, how can the group handle the third area of concern, that of the quality of the data present in the registry and any liability that may pertain? This is considered especially important given the potential for consumer access to the registry to enable, for example, a simply query about the need for a vaccination for a child. What if the registry says there is no need when, in fact, there is? Who is responsible for this—the public health department, all participants, the "health provider of record" for the child, or is there some other chain of responsibility? If it is an independent new entity, how can these problems best be anticipated and lessened?

Key Considerations

- Policymakers should educate and work closely with all community stakeholders.
- The potential for abuse or harm from publicly accessible databases should be carefully evaluated.
- Policymakers should help define and coordinate roles and responsibilities of professionals who are involved in delivery of services.
- Public health goals need to be balanced with the rights of individuals to privacy and confidentiality.

VI

Overview of Major Policy Issues

Several areas of national health information policy have undergone scrutiny in the context of the National Information Infrastructure and increasing use of information networks (Shortliffe et al., 1996; NAS, 1997). To date, most health information policy discussions at the national level have centered largely on provider-focused issues related to health data and information standards, data and network security, privacy and confidentiality of electronic data, telemedicine, and appropriate legislative and regulatory actions. Recently, however, the National Committee on Vital and Health Statistics (NCVHS) submitted to the HHS the first national health information policy document to explicitly integrate online and interactive consumer/patient applications (NCVHS, 1998). HHS is now studying approaches to building such a comprehensive, national health information infrastructure, including the respective roles of the public and private sectors.

In this chapter, the Panel outlines major policy issues that are relevant to the development, implementation, and evaluation of IHC applications (Patrick et al., 1999). Readers also should be aware that other policy discussions regarding the regulation of use and access to the Internet as it relates to electronic commerce, illegal activities, and minors' access to explicit materials, also may impact on IHC use. Information about these issues can be found elsewhere (CICAC, 1998; The Internet Society, 1998) and are beyond the scope of this report.

Privacy and Confidentiality

Privacy and confidentiality of personal health information are major issues for consumers, and these concerns are magnified when information is collected, stored, and made available online (NRC, 1997; CHCF, 1999). As the number and variety of developers and disseminators of IHC applications grow, consumer confidence about developers' ability or intent to ensure privacy will be challenged. For example, some employers are providing employee access to tailored health promotion applications at the workplace, but the increasing practice of monitoring employees' Internet use may discourage many people from accessing sensitive applications at their workplace. In addition, current technology allows developers and sponsors of Web sites to have access to the Internet addresses of users who frequent their site, and to place "cookies" on users' computers to track usage patterns and help the host site deliver personalized content. Developers should recognize that the ability to ensure privacy and confidentiality of responses is related to the accuracy of sensitive health information collected from users, and, thus, the quality of information and guidance provided back to the user.

Current policy discussions have focused much more on privacy and confidentiality protections for information collected during clinical encounters (e.g., electronic medical records, clinician-patient e-mail, and telemedicine encounters) than on information generated by use of IHC applications. These discussions should be expanded to recognize that personal health information is even more likely to be generated, transmitted, and stored within the context of using IHC applications (e.g., completing an online health risk appraisal, obtaining individually tailored health information or guidance; and maintaining a personal online health record). If the administrative simplification provisions of the Health Insurance Portability and Accountability Act of 1996 are ultimately enacted, the volume of electronic personal information exchange would increase significantly. Although such data flows are now only intended for administrative and financial purposes, health plans and providers could decide to build personalized interactive applications that draw upon patient/beneficiary profiles (HHS, 1999).

In the near future, personal health information will be generated during both clinical and nonclinical encounters in disparate settings, such as schools, mobile immunization clinics, public places, and the home. In fact, many health-related encounters may not even involve a health professional or a person, but rather, an intelligent software agent may be the intermediary. In addition, IHC applications may enable the collection, aggregation, and analysis of health information on a community level. Although public health and health services research may require legitimate uses of anonymous personal health information, policies and procedures for ensuring privacy and consent for release of personal health information will need to recognize these emerging points of health information collection and dissemination.

The need for confidentiality of personal health information must be balanced against the need for appropriate access to medical and related information for public health research, and resultant public health programs and policies. Although it is tempting simply to establish and enforce impenetrable "firewalls" between health-related records and public health researchers, policymakers must consider the value to public health of understanding the biological, behavioral, and environmental factors that can influence health and disease in populations. Research on approaches and models that can serve this vital need—while maintaining confidentiality—should be a high priority. This is particularly the case as research into the genetic basis of health and disease (e.g., the Human Genome Project) is augmented by complementary research into the behavioral and environmental modifiers of those determinants.

Several private sector efforts are emerging that promote assurance of data privacy for personal data collected over the Internet. For example, one nonprofit organization has developed a branded, online "seal" that signifies a Web site's adherence to privacy principles and their agreement to disclose information gathering and dissemination practices (TRUSTe, 1998). This and other initiatives reflect the public's desire to be clearly informed about exactly how the data they submit will be used.

Oversight and Regulation

There has been relatively limited discussion and no consensus on whether and under what conditions IHC applications should be regulated by government agencies. Some developers fear that government regulation of emerging fields, such as IHC, will stifle innovation and create bureaucratic hurdles that compromise the timeliness and marketability of applications. Others, including some consumer advocates, believe that in a field with many potentially serious consequences, such as IHC, regulation should remain an option in the absence of effective industry self-regulation. Given their mandate and history, at least two Federal government agencies may have potential jurisdiction over IHC applications. The Food and Drug Administration (FDA) regulates pharmaceuticals and medical devices and the Federal Trade Commission (FTC) oversees some aspects of advertising and trade. Several leading health and information technology organizations have outlined a proposed FDA role in the regulation of "clinical software systems," including some IHC applications (Miller and Gardner, 1997). The FTC has monitored health Web sites for false and deceptive claims and practices (FTC, 1997), but there is no systematic review and follow-up. With online health and medical advertising projected to grow from almost nil in 1996 to about $265 million in 2002—half of which is direct-to-consumer advertising by pharmaceutical companies—this issue will be increasingly important (Jupiter Communications, 1998). As with false and deceptive mass media advertising, government agencies and consumer interest groups may choose to exert oversight and monitor this situation. Government regulation of IHC may be more likely if developers do not adopt minimum standards of self-evaluation and quality control.

As IHC applications become more sophisticated, their power to persuade people to make substantive health decisions will rise sharply. Their potential to perpetrate fraud and deception will also increase. Some oversight of IHC content may occur through the extension of existing mechanisms for certification, licensure, and accreditation of health care facilities and systems. Because of the newness of IHC applications, and the difficulty in anticipating the kinds of safety and effectiveness problems that might result from their use, it is likely that legal cases and resulting case law will influence the policy environment for IHC application development and adoption.

Liability

The extent and nature of liability associated with IHC applications are unclear. Providing medical advice through IHC applications, including Web sites, increases potential liability for developers. This may be especially true for more sophisticated applications that provide decision support in high-consequence areas. As IHC applications become more complex and widespread, flaws in design or output may appear and cause unintended harm. In addition, it is unclear to what extent independent developers are legally responsible for multifunctional applications. One example of this may be a health plan that is being sued because of erroneous clinical advice provided by their “ask the doctor” feature which is closely integrated with a health information module that was developed by an external developer group. To what extent the developers, sponsors, content providers, or others involved in the design and implementation of the application will be liable for damages is unknown. In the absence of precedents in this area, future legal action and case law may provide some clarity on these issues.

Accreditation and Certification

Two major models for promoting quality improvement for IHC are accreditation of developers (where a developer’s ability and capacity to develop high-quality and effective applications are evaluated) and certification of applications (where specific applications are evaluated for quality and effectiveness). Examples of this are accreditation and certification of health care providers and consumer products by private organizations such as the National Committee for Quality Assurance (NCQA), the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), Underwriters Laboratory, and the American Academy of Pediatrics. Applying these approaches to IHC developers and applications may be feasible in the future but it does not seem possible to implement them now. There are several major differences between accreditation of IHC developers and health professional schools, hospitals, and health plans. Developers can quickly switch focuses and strategies at the whim of shareholders or the market. There is also concern that such approaches would be discriminatory against smaller developers and hinder creativity because they are less likely than large companies to have the resources to fulfill the requirements of a formal comprehensive accreditation and/or certification process.

Another approach to quality improvement is to implement rating systems or other mechanisms to facilitate evaluation and benchmark IHC applications for consumers. Many examples of such tools are already in use (Jadad and Gagliardi, 1998; Kim et al., 1999). It is unclear, however, if current systems are effective in promoting quality or changing consumer behavior. Further efforts are needed to explore new models that are valid, address the dynamic nature of new technologies, and can be readily understood by the public. Several consumer-oriented organizations, such as Consumers Union, have successfully implemented rating systems for many consumer health products.

Public Investment in Development and Research

Private capital for IHC development comes from investors who purchase equity in the company or corporations that sponsor the activity. Public support includes grants or contracts, and potential specific financial incentives, tax relief, or other forms of indirect support. Many government agencies, particularly those within HHS, are actively involved in developing Web sites that provide health information. It is unclear what proportion of government research and demonstration grants are being used to support IHC development in the private sector. The Small Business Innovation and Research grants given by HHS agencies, and the Telecommunications and Information Infrastructure Assistance Program, the National Institute of Standards and Technology, and the Advance Technology Program of the US Department of Commerce, are common sources of such support (Appendix C).

There may be at least two situations in which public funding of IHC is warranted. One is to support development of applications that address health issues for which there is no or limited commercial interest, such as applications for rare health conditions and underserved populations, and those that enhance the public health. Without public support or incentives, the capital needed to develop them may not be available. Another potential area for public support is in sponsoring demonstrations or case studies of the feasibility, utility, and effectiveness of IHC interventions that contribute to improving health and reducing health care costs.

Payment and Reimbursement

Either government or private payers may set reimbursement policy for IHC-mediated services. Changes in Medicare and Medicaid reimbursement policies often drive reimbursement policy for private insurers. The Health Care Financing Administration (HCFA) has approved reimbursement for real-time clinical consultations in rural areas within specific parameters, but will not cover IHC-related functions (HCFA, 1998). Government program reimbursement for IHC-mediated services seems to be relatively low on the priority list. Private health plans and insurers also may not be proactive in this area but they may be more likely to initiate reimbursement of specific IHC applications if they are proven to be cost-effective. More frequently, health plans are introducing Internet-based consumer services as a customer service, or, less frequently, as part of disease management programs.

Integration of IHC With Clinical Practice, Public Health, and the Workplace

Clinicians, health care organization administrators, and public health officials are grappling with how to integrate IHC into clinical care and public health. What types of IHC applications are appropriate for use in clinical and public health practice? What kinds of technology access should health professionals have? What technology needs and training are necessary to support them? How much should clinicians and public health professionals rely on IHC to fulfill their patient and public health education functions? What kind of support do clinicians and public health professionals need from administrators and support personnel to assure that access to IHC applications improves the efficiency and effectiveness of their interactions with patients and clients? How can systems be designed to alert occupational safety and health professionals about new workplace hazards?

A major obstacle to clinicians promoting the use of IHC and integrating it into their practice is the time constraints on clinical encounters under which many clinicians operate. Some clinicians, for example, believe that patients who frequently use the Internet to research health information are time-intensive to manage, and that they do not have the time to help patients interpret the information they encounter. On the other hand, IHC may help alleviate some time and resource pressures because referring patients to quality IHC applications may augment the limited time clinicians typically devote to patient education. However, in some settings, these efficiencies cannot be realized unless there is substantial administrative support for redesign of processes of care. Certainly reimbursing clinicians for time spent assisting patients with IHC or other models that provide clinicians with time to assist patients would encourage them to take such an active role. There are also health care providers who are reticent to promote the use of IHC because of the potential threat to their authority or change in the traditional patient-provider relationship. Information and communication technologies will clearly change some paradigms in health care delivery (Blumenthal, 1998), but it is unclear to what extent it will impact on the patient-provider relationship. In many cases, the people who ultimately implement and integrate IHC into health care or public health systems are nurses and nonclinical personnel, such as office managers and administrators.

IHC applications overlap with two other information technology applications in health care: clinical information systems and telemedicine. There is considerable private investment in electronic clinical information systems and telemedicine. These systems and projects typically focus on facilitating clinical care delivery in the context of a health care setting and seldom integrate the health information and support functions of IHC applications. There is, however, some movement toward integration of IHC with clinical care delivery as exemplified by initiatives at several managed care organizations (AAHP, 1999). To ensure that electronic medical records, telemedicine applications, and other clinical systems are interoperable, the design of these and public health information systems and applications will need to be based on recognized standards and open platforms. As technology infrastructure and software tools improve, comprehensive interactive applications that encompass clinical, public health, and IHC functions are likely to emerge. The "National Health Information Infrastructure" envisioned by the National Committee on Vital and Health Statistics (NCVHS) would promote this trend (NCVHS, 1998).

Efforts are being made to strengthen access to public health information and communication among public health practitioners. For example, the Information Network for Public Health Officials, initiated by the Centers for Disease Control and Prevention (CDC) in 1992, supports public health professionals in carrying out the core functions of public health (Baker et al., 1995). Additional initiatives to enhance public and health professional access to current public health information may help integrate such information into IHC applications that promote health and use of preventive services.

The extent to which public health departments are reliant on advanced information and communication technology to facilitate health services delivery and public education varies greatly. As with many health issues, smaller health departments will have challenges integrating IHC applications into their operations because of the lack of resources and technical expertise. It is likely that national, state, or regional efforts to develop and disseminate models of integration of IHC into public health practice will be necessary. Continuing reductions in costs of computer hardware and communications services may make these technologies more affordable to local health departments.

Internet-accessible computers are ubiquitous in many work settings, but they are generally used for reasons other than health and safety. Although some occupational health and safety professionals report using the Internet for health information, it is unclear how many of them are aware of the range of IHC resources available, or whether these resources have been, or could be, integrated into occupational health and safety programs. It is also unclear whether existing IHC applications are sufficient to meet the diverse needs of US worksites. Issues of employer-employee trust will need to be addressed for successful implementation of IHC applications in the workplace.

Access to IHC

IHC may help reduce health disparities through their potential for promoting health, preventing disease, and supporting clinical care for all. Recent data indicates that the profile of Internet users may be becoming more representative of the general population (PRCP&P, 1999), but the poor and others who have preventable health problems and lack health insurance coverage are unlikely to have access to such technologies (Eng et al., 1998; US Department of Commerce, 1998). Data shows that lower income families, rural households, African Americans, and Hispanics are less likely to own a computer or have Internet access than other groups (US Department of Commerce, 1998). For example, in 1997, only 2 percent of rural US households with incomes between $5,000 and $10,000 had access to online services compared to 50 percent of families with incomes greater than $75,000 in 1997.

Enhancing access to health information and support may promote more efficient use of services (Pane et al., 1991; Stern et al., 1991), reduce the total costs of illness (Gustafson, Peterson-Helstad et al., 1995), and help avert preventable health conditions that disproportionately impact lower income populations (Shimakawa et al., 1994; Liu et al., 1996). Although data on the impact of IHC on underserved populations are limited, some studies suggest that it can improve health knowledge, attitudes, and cognitive functioning (Gustafson, Hawkins, Boberg, Bricker, Pingree et al., 1994; Carroll et al., 1996); enhance emotional well-being (Gustafson et al., 1993); and reduce utilization of health services without impacting health (Alemi, Mosavel et al., 1996; Gustafson, Hawkins, et al., 1999). If these effects can be consistently replicated, substantial improvements in public health and health care cost savings can be realized among the underserved. In addition, as reliance on online health information and support resources become more common for routine functions such as making appointments and communicating with health professionals (Zallen, 1995), access to IHC becomes an increasingly essential component of health services access and health maintenance.

Barriers to IHC access include those related to technology infrastructure access and those associated with the characteristics of nonusers and the information and applications themselves. Certain populations also have difficulty accessing online health resources because most IHC applications are designed primarily for educated, literate, and nondisabled audiences. Many people have inadequate skills in science, technology, or reading literacy; cannot understand or use health information; have a physical disability; or cannot communicate in English (Williams et al., 1995; Baker et al., 1996; Yom, 1996; Williams et al., 1998; WWW Consortium, 1998).

Underserved populations are keenly interested in using technology including the Internet (US Department of Commerce, 1995; Hoffman and Novak, 1998). Studies show that, with appropriate training, many underserved groups including low-income families (Kinzie et al., 1993; Watkins et al., 1994; Gropper et al., 1995; Bier et al., 1996; Kraut et al., 1996); residents of inner cities, housing projects, and rural areas (McTavish et al., 1994; Alemi, Stephens, Muise et al., 1996); disabled persons (Hassett et al., 1992); the elderly (Ellis et al., 1991); racial/ethnic groups (Gustafson et al., 1994; Pingree et al., 1996); and drug users (Alemi, Mosavel et al., 1996; Alemi, Stephens, Javalghi et al., 1996); can successfully use technology to address health concerns. Studies suggest that low-income consumers are savvy about persuasive marketing communications (Alwitt and Donley, 1996), want independent information when purchasing a range of products (Mogelonsky, 1994), and, thus, can critically evaluate information.

Providing universal access will require a collaborative effort among a wide variety of stakeholders on all levels (Milio, 1996; McCray and Maloney, 1997). Without external intervention, market forces are unlikely to address the needs of those without access. While universal access at home is ultimately desired, for the near term, until home access is universally available and affordable, universal access may necessitate a combination of private (i.e., home) and public (e.g., schools, libraries, public buildings, post offices, shopping malls, community centers, health care facilities, places of worship) access points (Eng et al., 1998). The Telecommunications Act of 1996 provided support for universal access to advanced telecommunications by authorizing universal service discounts to K-12 schools, libraries, and rural health care and public health facilities, but full implementation of the program is uncertain (FCC, 1998). Additional models for supporting access that have multisector backing may be necessary.

VII

Recommendations

The following recommendations of the Panel stem from reviews of published data and studies, discussions among Panel members, interactions with other participants at Panel meetings and presentations, and comments and suggestions from the liaisons to the Panel during the course of more than 2 ½ years. Although the ideas presented here resulted from careful and systematic evaluation of available information and data about IHC by many experts, the science base on IHC is limited, and these recommendations should be viewed as informed guidance rather than as definitive directives. The Panel's recommendations are intended to promote and focus debate and discussion among IHC stakeholders—those who develop applications, those who use them, those who purchase them for others to use, and those who establish policies that affect their use. Additional consensus-building processes could build on and further refine the Panel's suggested guidance in this evolving field. Disagreements about some of the Panel's recommendations may emerge because some of the issues around IHC are controversial and challenge traditional roles and systems. In these cases, colleagues are encouraged to offer differing perspectives on these issues and engage in a constructive public dialog to advance the field of IHC.

Vision

The Panel developed the following vision for IHC:

> *"Interactive health communication will play an essential role in enhancing health, minimizing total burden of illness, and optimizing relationships between individuals and health professionals."*

The Panel believes that IHC has the potential to contribute substantially to the health of the public. Individual health status can be enhanced through the use of IHC for health promotion and disease prevention. By reaching, informing, and motivating people in innovative ways, these technologies can augment public health efforts and minimize the total burden of illness and its economic and social costs. By providing peer and emotional support, IHC has the potential to alleviate the adverse social and emotional consequences of illness, and, perhaps, improve functional status. The Panel believes that IHC will not replace health care professionals, but complement what they do. Indeed, IHC could strengthen the relationship between patients and health professionals in several ways. For example, by providing appropriate health information to patients outside the context of an office visit, patient-provider encounters may be better focused and more efficient. By enabling and facilitating shared decisionmaking processes, patients are more likely to achieve their desired outcomes and express satisfaction with their care.

Roles and Responsibilities of Stakeholders

A preferred future for IHC will not materialize without a concerted effort to nurture its potential benefits and to minimize its potential for harm. As a first step, the roles and responsibilities of stakeholders need to be clarified. The Panel suggests a basic framework as presented in Table VII-1, not as a fixed model, but rather as a starting point for further discussions among stakeholders.

Table VII-1. Potential Roles and Responsibilities for IHC Stakeholders

Stakeholder	Roles and Responsibilities
Developers	• Design and market IHC applications in a responsible manner. • Ensure that applications are of high quality, effective, and responsive to significant needs of users.
Purchasers	• Decide what, if any, IHC applications are purchased and/or implemented within their organization. • Ensure that applications are selected based on their effectiveness and appropriateness for the specific audience and needs. • Implement and operate applications appropriately to ensure that all those in need have reasonable access to them.
Health professionals, educators, librarians, & other information intermediaries	• Assist and guide patients/clients in locating reliable sources of information and support and in selecting and using IHC applications. • Ensure that patients/clients are supported adequately in using applications. • Make use of IHC applications to stay informed of current applications and to serve as a role model for patients/clients. • Promote access to IHC among patients/clients.
Researchers	• Conduct basic and applied research to improve knowledge and effectiveness of IHC. • Disseminate results of research to other stakeholders, including developers.
Consumers	• Use IHC applications in a responsible manner and evaluate applications before use. • Advocate for development of and access to high-quality applications. • Provide feedback to developers and implementers. • Participate in a constructive manner (e.g., being supportive in discussion groups).
Policymakers	• Monitor and assess how IHC applications are being used and their impact on personal and public health. • Ensure that policies promote quality and ensure safety while not hindering innovation and adoption of use. • Ensure that all populations have access to applications. • Implement policies that promote use of effective applications and the best interests of users and the health of the public. I

There is considerable overlap in these roles and responsibilities. In some cases, an individual stakeholder may have multiple roles as part of his/her job.

For example, the same health professionals may function as developers when they serve on the health plan's Web site development committee, may assume purchaser roles when they participate on the information technology committee on software/hardware procurement, and may play the roles of information intermediaries when they help patients interpret information downloaded from the Internet.

The potential roles and responsibilities of stakeholders in evaluation of IHC deserve special emphasis. Although frequently considered the purview of researchers and developers, all stakeholders including consumers, health professionals, purchasers, and policymakers can play an active role in evaluation. Consumers and purchasers can use evaluation information to help in decisions regarding the purchase and use of IHC applications. They can help specify performance criteria, reasonable costs, and outcomes for use of the product in specific circumstances. Consumers and purchasers also should benefit from evaluating the extent to which the application can "stand alone" as opposed to augmenting existing health information and support strategies. Does the application add value or is it merely more "bells and whistles?" Policymakers can ensure that financial and clinical environments are conducive to IHC evaluation, including promoting incentives for use of evaluated products. Policymakers also have a role in evaluating the impact of IHC on health care and public health systems.

The role of clinicians and other health professionals deserves special mention because their training in scientific methods enables them to promote evaluation and quality improvement. As societal and health care trends pressure consumers to assume more responsibility for their health care, they will need assistance in this capacity. For example, rapid advances in medical technology require people with chronic health conditions—and their caregivers—to have fairly high-level skills in, and knowledge of, technology and health. Clinicians can help in this regard by helping patients and caregivers identify and evaluate the quality and utility of IHC applications and other information resources (Engstrom and Brown, 1996; Eytan, 1997; Krishna et al., 1997; Renner, 1997). This is particularly important for complex health problems where patients and families may have difficulty navigating and evaluating the spectrum of health information resources. Clinicians also are in a position to confirm that patients understand the health information they find regardless of its source. Suggested specific activities for clinicians in promoting an "information-friendly" practice are presented in Appendix F.

Similarly, an appropriate role for public health professionals is to assess IHC applications and other information resources available to the community and determine how online health resources can be used to complement other community health resources. One of the traditional "safety net" roles of public health—to address community health problems and needs of population groups that are not being served by the established health care system—also can be applied to IHC. In this context, public health professionals, in collaboration with other stakeholders, should take responsibility for ensuring that all populations have access to appropriate health information and support.

Major Strategies

In deliberating about the initiatives that could move the field of IHC forward and achieve the vision proposed in this chapter, the Panel was impressed with the need for a multidisciplinary, multipronged approach.

The Panel proposes four overarching strategies to achieve the Panel's vision for IHC:

1. Strengthen evaluation and quality of IHC
2. Improve basic knowledge and understanding of IHC
3. Enhance capacity of stakeholders to develop and use IHC
4. Improve access to IHC for all populations

The Panel chose to put a primary emphasis on promoting evaluation because it believes that widespread evaluation and dissemination of results will drive the widespread availability of high-quality and effective applications. Because of the newness of the field, scientific knowledge about many aspects of IHC is very limited. Greater knowledge is needed to improve the effectiveness of IHC, inform application design and implementation, and, ultimately, further appropriate public policy. The Panel also identified major gaps in resources available to application developers and shortcomings in the skills of users. These deficiencies will need to be addressed to ensure the continued development of innovative applications and the ability of intended users to take full advantage of IHC. Finally, enhancing access to IHC for all populations is essential because, without equitable access, evaluation efforts will be incomplete and the potential for IHC to provide benefits to entire communities is not likely to be realized.

In the remainder of this chapter, the Panel identifies the major areas within each strategy and outlines specific tactics that could be used to achieve a preferred future for IHC. The main recommendations of the Panel within each area are in ***bold italics***.

STRATEGY 1. STRENGTHEN EVALUATION AND QUALITY OF

APPLICATIONS

Evaluation of Applications

The Panel believes that promoting widespread evaluation of IHC applications should be a central strategy for improving their quality and effectiveness. Because of the emerging nature of the technology and the potential for harm, there is a need to adapt an evidence-based approach to IHC. However, in applying this approach, it should be recognized that it may not be sufficient in all situations and that all types of data and evidence, not just statistical significance, should be considered when appropriate. There also is a need to define what is a "gold standard" for adequate evidence. Ultimately, a balanced approach to evaluation—one that promotes quality and considers the potential risks of an application—is indicated.

In light of these issues, the Panel believes that evaluation of IHC applications should: 1) be *practical* in that evaluation methods reflect real-world limitations; 2) be *proactive* in that it seeks to prevent problems; 3) have a *clear purpose* of how results will be used to improve application quality; 4) be a *shared responsibility* in that all stakeholders participate; and 5) be *integrated* into the product development cycle in that evaluation methods are used to strengthen the software quality assurance process and are implemented throughout the product development process, from conceptualization through post-marketing surveillance.

To spur widespread evaluation activities, new evaluation models that facilitate evaluation for developers and that help users and purchasers assess quality and appropriateness need to be developed. These approaches may be necessary because current evaluative strategies were developed for relatively static health interventions that do not lend themselves well to the dynamic nature of new and emerging media. Agile evaluation methods that can adapt to the evolving field of IHC are essential. It is possible that appropriate evaluation systems will need to rely on many of the same advanced technologies that IHC applications are using. For example, software agents may be used to detect system changes and alert potential users. They may be used to extract or identify specific changes so that users, developers, and others can periodically examine the modifications without having to evaluate the whole system again. These technologies could identify, assuming accurate and timely reporting, when changes occur in an application, including sponsorship, content, and skills of the development team.

- ***Purchasers of IHC applications should require developers to integrate evaluation methods into product development and implementation as a condition of purchase.*** Developers should be proactive and implement quality control and evaluation methods throughout the development process to prevent the release of ineffective or harmful applications. To encourage evaluation, prototype evaluations of applications at all levels within select topic areas (e.g., topics where there is substantial potential to do harm) could be made available to developers to serve as a template for future evaluations in similar areas. In situations where developers are unwilling to implement such controls or evaluation methods, health professionals (as individuals and through professional organizations), purchasers, consumers, and consumer advocates will need to exert pressure on them to do so. Similarly, consumers should insist on using only evaluated products. These practices will encourage the IHC industry to conduct evaluations and promote a norm of evaluation. In return, purchasers must be willing to implement and pay more for evaluated products. It should be noted that frequently purchasers, rather than developers, have ultimate control over product implementation, and they should work closely with developers to ensure that products are implemented appropriately. Because knowledge about effective implementation is limited, more research is needed in this area. Those who deploy applications should recognize that assessment of a product independent of its context might not be fully informative or adequate.

Disclosure of Information About Applications

Users and purchasers need access to essential information about an application (e.g., identity of the developer and sponsor, purpose and content of the product) in order to make informed decisions about whether the application is appropriate for their needs. In other sectors, such as the food processing and motor vehicle industries, essential information about the producer and components of the product is routinely disclosed to consumers. Currently many IHC applications do not publicly disclose such information about their products. In some cases, even basic information about the identity and background of the developers or sponsors of the product is not revealed. Providing full disclosure of the essential elements of their application may be in the best long-term interests of developers.

- ***Developers should publicly disclose information about their IHC application including identity of developers and sponsors, purpose of the application, source(s) of content (including disclosure of advertising), privacy protections, whether and how the application was evaluated, and the results of evaluations.*** Purchasers and users should expect to see this type of information before purchasing or using the product. The Panel's "evaluation reporting template" could be used as a guide for sharing evaluation results with potential users and purchasers and for planning evaluations (Appendix A). Developers should also consider posting a "disclosure statement" accompanying their product that presents key information about the application and/or developers (e.g., conflict of interest information) to allow consumers to compare applications (Appendix B). This type of labeling information could be posted as part of any Internet-based IHC application.

Voluntary Quality Standards

In the last few years, there has been much discussion about quality standards for health-related information on the Internet and other IHC applications. By implementing such standards, developers may be able to avert government regulation. While recognizing the need for quality assurance mechanisms, many policymakers are reluctant to regulate this emerging industry for fear of hindering innovation and infringing on free speech. Several organizations have called for the adoption of voluntary quality standards for health-related Web sites (Silberg et al., 1997; HON, 1998). Quality standards should include consideration of the use and development of new search engines that rank or evaluate Web sites by reviewing content and links.

- ***Developers of IHC applications should adopt voluntary quality standards for application development.*** This could be accomplished through a variety of means. For example, an independent organization should convene developers and other stakeholders to establish consensus voluntary standards for the industry. Such standards could include mechanisms for consulting with and integrating feedback from topical experts and representatives of the targeted audience. In addition, to ensure the interoperability of IHC applications and related systems, including electronic medical records, telemedicine applications, and clinical information systems, these applications and systems should be based on consensus industry standards and open platforms. Further discussion and research are needed to examine the utility of evaluation standards for IHC applications, including outcome measures that would allow comparison of outcomes across applications.

Reviews of Web Sites and Other IHC Applications

Ensuring the quality of health information on Web sites is a major interest of policymakers and consumers. Currently, many organizations conduct reviews of health-related Web sites and some produce ratings based on a variety of criteria (Jadad and Gagliardi, 1998). Most of these organizations, however, do not focus their assessments on evidence of effectiveness. A review of explicit criteria proposed by rating organizations and others revealed that none suggested using evidence of application effectiveness as a criterion for quality (Kim et al., 1999).

- ***As a primary criterion for their review and rating of IHC applications, individuals and organizations that conduct reviews of applications should include information on whether and how the application was evaluated for effectiveness.*** Only evaluation results can help potential users judge the value and appropriateness of an IHC application for their specific needs. Including evaluation of the application as a criterion would encourage developers to conduct evaluation and make the results available to organizations and potential users.

STRATEGY 2. IMPROVE BASIC KNOWLEDGE AND UNDERSTANDING OF IHC

Research and Development

It is unclear if current market forces will appropriately focus the activities of developers on the high-priority, health areas for the nation. Because IHC development is occurring through the independent and uncoordinated efforts of many developers, both overlap and gaps in research and application development exist. In addition, priorities for demonstration projects have not been elucidated. For the field of IHC to move forward, many stakeholders, including the government, academia, developers, and consumer groups, will need to reach a consensus regarding a comprehensive agenda for basic and applied research, application development, and demonstration projects.

- ***Public and private sector organizations with an interest in health and technology should establish a formal process for identifying and addressing current knowledge gaps and priority areas for basic and applied research, application development, and demonstration projects.*** This could be initiated and supported by the Federal government, private foundations, and corporations. An independent and nonpartisan organization or an entity with representation from key stakeholders could be responsible for coordinating this collaborative assessment process. Priorities for application development and demonstration projects should be based on assessments of available and upcoming applications and on analyses of what health needs and populations are not being addressed. In setting and acting on priorities, it may be helpful to set specific consensus goals for improving IHC and then implement a series of breakthrough programs to push development activities for that period of time. For example, once a goal was agreed upon, stakeholders would be educated about the initiative, then a series of programs would be implemented to focus developers' efforts on the goal, followed by widespread demonstration projects.

Examples of areas in need of basic and applied research include: impact of IHC on behavior change and quality of life; population and individual differences in use and effects of IHC; effectiveness of different media in health communication and behavior change; effective user interface design; measurement approaches for assessing application efficacy and effectiveness; understanding concordance between patients' preferences and health choices as a measure of decision quality; relative effectiveness of IHC and alternative interventions (e.g., virtual versus in-person support groups); and IHC implementation models as they relate to professional and institutional adaptation and integration.

Examples of worthy application and demonstration projects include: community wide projects to improve population health; integration of IHC applications in health care settings; implementation of IHC in settings outside the context of the clinical encounter; projects that integrate delivery of care, preventive health, and access to information and support; models for implementing and maintaining IHC applications in organizations including workplaces; applications for the workplace, underserved populations, and other groups of low commercial interest; and projects that expand public access to IHC.

Public Funding Agencies

A variety of government agencies currently support research and development in IHC. As with other health issues, coordination of funding programs is sometimes lacking. In a rapidly evolving field such as IHC, it is particularly important for public agencies to coordinate their efforts to ensure that priorities are sufficiently addressed and that redundancy is minimized.

- ***A cross-governmental and interagency initiative to coordinate Federal and State funding in the area of IHC should be established.*** Agencies with oversight responsibility should consider initiating this activity. Although coordinating funding programs is important, agencies should be allowed to maintain autonomy in funding decisions according to their priorities and interests.

Impact of IHC

Some researchers have attempted to document the impact of specific IHC interventions in select populations, but there are no studies of the impact of IHC on the health, economic, and social outcomes of large populations. Data from such studies would be extremely useful as a basis for policy and funding decisions of policymakers, purchasers, and investors.

- ***A long-term initiative to monitor and assess the health, economic, and social impact of IHC should be established.*** The Federal government, private foundations, and corporations should support such an initiative. Monitoring and assessment could be conducted by both public and private sector entities. Analysis and evaluation of IHC should focus on quantifying the likely impact of IHC on health status, the economy, and social networks. Questions to be addressed through such an initiative include: How are IHC applications being used and which populations use them? What is their impact on total burden of illness, public health, organizational behavior, and health care systems? What is the cost-effectiveness of IHC versus other interventions to improve health? What types of health effects, both positive and negative, can be expected? Does IHC optimize health care utilization and reduce costs? If so, under what circumstances? Are there ancillary benefits or costs, such as improvement in quality of life or sense of self-efficacy and well-being? Does the impact differ by population group? Will it increase or reduce the gaps in health status among certain population groups? How does IHC affect the relationships between health professionals and patients and among individuals themselves?

Policies and Practices of IHC

There is no formal activity to monitor the impact of IHC-related policies at the local or national levels. Such a program would be a means by which consistency of policy and regulatory oversight might develop. For example, consistency or compatibility of standards for technical interfaces and terminology can help foster innovation of IHC application development by clarifying the conditions under which they would be expected to operate. Unless some means exists to objectively monitor policies and practices influencing IHC, the totality of the policy environment is not likely to be understood or improved.

- ***Programs to monitor and analyze trends in IHC policy development should be established for the purpose of improving policy.*** Policymakers in the public (e.g., government) and private (e.g., foundations) sectors should consider supporting this activity. Government agencies and private sector policy research organizations are likely candidates to monitor trends. Appropriate focus areas for monitoring include: impact of policies and practices on innovation, dissemination, and adoption of IHC; best practices and lessons learned from successes and failures; policies pertaining to the liability of IHC developers and those who deploy them; and policies related to public access to community-focused IHC. The results of these analyses, including success stories and successful strategies as well as evidence of harm, should be rapidly disseminated to developers and other stakeholders.

Privacy and Confidentiality Related to IHC

Policymakers must ensure that appropriate monitoring of IHC quality occurs. This is related to the recommendation about monitoring impact of IHC but is distinctly separate. Although that recommendation relates to the impact of IHC on health-related indicators, such as health status and cost-of-care, there is a need for a system of ongoing quality assessment and oversight for IHC. A central question is who will monitor how those deploying IHC address issues of privacy, confidentiality and security of the information they collect? The Panel is not aware of an entity or groups of entities that have been identified and designated to assume responsibility for assuring that this happens. The lack of vigorous debate about, and subsequent implementation of, optimum approaches to ensuring online privacy and confidentiality are serious barriers to IHC use. Standards for assuring privacy and confidentiality of traditional health and medical data are promulgated by health system accrediting agencies such as JCAHO, and sanctions for breeches of confidentiality can be brought by state licensing boards or other governmental or professional groups.

- ***Entities responsible for assuring the quality of personal health services, in conjunction with appropriate government agencies, should determine where responsibility and authority rests for ensuring the privacy, confidentiality, and security of IHC-related information.*** Candidates to participate in this discussion include JCAHO, the Accreditation Association for Ambulatory Health Care, Inc., NCQA, HHS, state medical boards, state health care licensing agencies, and other appropriate legal and consumer groups. Groups such as the NCVHS and similar organizations could also provide technical and policy expertise on these deliberations. As a corollary, all current efforts to develop policy on the privacy and confidentiality of personal health information should include within their purview information generated through Internet-based applications.

STRATEGY 3. ENHANCE CAPACITY OF STAKEHOLDERS TO DEVELOP AND USE IHC

IHC Application Development Resources

Many developers, especially individuals, small companies and nonprofit organizations, have limited resources. Development and dissemination of public domain application development resources can benefit the field by reducing duplicative efforts and avoiding reinvention of commonly used objects, tools, and other materials. This will free up resources and allow developers to focus on innovative application design, and enable small or nonprofit developers to more easily create IHC applications for underserved or low-commercial interest groups.

- ***A clearinghouse for public domain objects and tools, raw materials, and information resources for IHC applications should be established for public use.*** Government agencies, corporations, and commercial developers should support this effort. Developers should be given an incentive to donate objects and resources to the public domain. This could be built into project requirements for government or private foundation grants or accomplished through requirements associated with State or Federal licensure.

Common functions for which public domain objects and tools are needed include those that:

- support evaluation;
- ensure privacy, confidentiality, and security;
- automate data collection;
- obtain informed consent;
- track individual health behaviors over time;
- assist in decisionmaking;
- conduct health risk appraisals;
- perform tailored searches on the Internet and scientific literature and other databases; and
- spur the development of novel types of applications.

Examples of public domain information resources needed for IHC development include:

- databases of needs-assessments for specific health conditions and specific populations;
- bibliographies of high-quality research studies, evaluations, and case studies;
- database of potential public and private sector funding sources and partners; and
- databases of frequently asked questions and responses.

Collaboration and Partnerships

Many developers have limited expertise or experience in technical or topic-specific areas that are necessary for application development and evaluation. There is often a disconnection between basic research conducted at academic institutions and application development activities of commercial companies. The demands and pressures of the commercial sector to bring products quickly to the market may sometimes run counter to the deliberate pace of academic institutions. Examples of collaborative projects exist but it is clear that many projects are duplicative (e.g., many Web sites offer similar information on the same health topics) and some may even replicate failed approaches. This phenomenon, unfortunately, also is common in many other areas of science and engineering. Increased exchange of information among developers, and between developers and other stakeholders, may result in more efficient uses of unusual expertise and limited resources, and ultimately improve the quality of applications. Of course, some developers will be constrained in participating in collaborations or partnerships because of their desire to preserve proprietary approaches and maintain a competitive edge.

- ***Government agencies, foundations, and investors should strongly encourage IHC developers to explore academic-industry collaborations and other partnerships that enhance application quality and evaluation by funding developers who propose these activities.*** Such arrangements should include sharing expertise in IHC design and evaluation. Academia-industry collaborations will expedite transfer of basic research findings to innovative application development and encourage evidence-based approaches to application design. Other mechanisms that could improve information exchange among developers, and between developers and other stakeholders, include the establishment of multisector conferences and multidisciplinary committees and work groups.

Health and Technology Literacy

Components of health and technology literacy include computer and technology use skills, reading ability, and ability to comprehend health- and science-related concepts. Many individuals have inadequate technology skills, such as the ability to use a computer or navigate the Internet. Although young people are becoming increasingly adept in using computer-based communication technology, many older individuals and others who are at high risk for adverse health conditions, will need training to be proficient. In addition, some cannot utilize IHC applications because they do not understand health information or the medium used is not appropriate for them (Williams et al., 1995; Baker et al., 1996; Eng et al., 1998). About half of the US population has rudimentary or limited reading skills (NWGLH, 1998). People with inadequate health literacy have a variety of communication difficulties that may interact to influence health outcomes (AMA, 1999). Improving these skills is important because most IHC applications are primarily text-based and designed for educated and literate audiences. IHC applications should take advantage of interactive media to address the needs of low literacy audiences. In addition, the ability to interpret and personalize scientific information will be increasingly important as individuals assume more responsibility for their health-related decisions and seek health information and support outside of the traditional health care setting.

- ***Programs to monitor and improve public literacy in science, health, and technology should be supported by government agencies, private foundations, corporations, and nonprofit organizations.*** Such programs should include building skills in use of emerging technologies, improving comprehension of scientific information, supporting reading skills, enhancing capacity to utilize health information in the context of an individual's environment and needs, and improving people's ability to distinguish between high- and low-quality information and applications. To gain that capacity, training may be needed in areas such as critical thinking, judgment, risk communication, and understanding of bias and levels of evidence. To ensure that applications are useful to the widest audiences, developers will need to focus on producing easy-to-use programs.

IHC Intermediaries

Some consumers do not have the skills or experience to successfully and completely use IHC applications. These individuals will require assistance from health professionals, peers, or others who are experienced and skilled in using technology and interpreting health information. Within the context of the health care setting, much of this responsibility may fall on health professionals, including health educators and clinicians, many of whom will need additional training to assume this role. Educators, medical and other librarians, and other information intermediaries also will play an increasing role in helping the public select and interpret health information. Within health care organizations, performance measurement tools can help focus institutional resources and attention on ensuring that members have access to quality health information and support.

- ***Health professional schools should include IHC in core curricula to promote their integration with clinical practice.*** New "health information professionals" or "health infomediaries" also may need to be trained to advocate for patients and assist them in evaluating, selecting, and using IHC resources to complement professionals, such as medical librarians (NNLM, 1999), who may already serve in this capacity. Health professional training should be aimed at improving clinical skills and familiarity with IHC as a means of promoting health and managing health conditions. While physicians will probably need to take part in this activity in the clinical setting, their available time will likely remain at a premium. Therefore, nurses or lay "health information professionals," including librarians, may eventually assume much of the responsibility for this activity. In addition, health professional societies and health plans should sponsor in-service and continuing education training opportunities for health professionals in this area. Because IHC will become an increasingly important component of patient-health resources, new clinical practice models that effectively integrate IHC as an adjunct to clinical care will emerge.

- ***Performance indicators that monitor health plan efforts to help members and patients locate and critically assess health information and support resources should be developed and implemented.*** HEDIS (NCQA, 1999), which is used by large employers and other health care purchasers to compare and evaluate the performance of large managed care organizations, is an example of an appropriate mechanism for such indicator development. In addition, health care organizations should make high-quality resources available to members and allow time and/or reimbursement for the services of health professionals who help patients and family members locate and evaluate health information and support resources. To enable clinicians to help patients evaluate information brought into the context of the clinical encounter, the care setting will need to support clinicians in this activity given the many competing demands on their time. In addition, health care organization administrators will need to examine and update models for delivering care that are consistent with the increasing availability of IHC applications.

Implementation and Financial Models for IHC

The effective dissemination of IHC applications has a number of obstacles and will not occur unless there are appropriate implementation and financial models to support them. Little is known about implementation barriers, their impact, or how to overcome them. A central implementation hurdle is in modifying the roles of those who play a key role in system implementation. An attractive and content-rich application is only one component of a successful system. The successful implementation of applications may require complex organizational changes. Job descriptions, reporting relationships, and organizational structures need to be considered in implementation activities. For example, issues related to modifying routine clinical practice so that clinicians refer patients to these systems and support them in their use are important. In addition, how can mechanisms be established to identify, recruit, and train potential users who are likely to benefit from such systems in a timely manner? Other implementation challenges include: overcoming clinician resistance for varying reasons; developing appropriate support mechanisms and allocating resources; involving key personnel early in the adoption decision; clarifying organizational priorities for the system; and supporting infrastructure and equipment costs of providing computers and access devices.

- ***Process and organizational models for effective implementation of IHC applications should be developed and evaluated.*** Studies are needed to identify and understand organizational, institutional, and other barriers to implementation of applications. Initiatives to develop and test strategies to reduce or overcome those barriers are needed.

Another major obstacle to widespread dissemination of IHC applications is the relative lack of appropriate financial models used by developers. While consumer demand for IHC applications seems to be substantial, the appropriate business model is not clear. Moreover, perceived costs of adopting and integrating IHC applications may deter some purchasers and providers who are considering their implementation.

- ***Financial models should be developed and tested to determine whether they support appropriate use of effective IHC applications.*** Further research is needed to understand why some IHC initiatives fail or succeed so that effective models for financing can be promulgated. Such models may include reimbursement by health care payers, such as private health plans and Medicare and Medicaid. Payers should ensure that reimbursed applications are technology-neutral, evidence-based, and have been evaluated for effectiveness. The government can help this process by jump-starting the market through demonstration programs. As a major insurer, the government could help by expanding the definition of telemedicine to include online health education services so that these services can be reimbursed. The government could also work with the industry (including the venture capital firms) to understand market impediments. Cooperation between the government and the industry might help alleviate some of the market uncertainties and stabilize the IHC industry.

STRATEGY 4. ENSURE EQUITABLE ACCESS TO IHC FOR ALL POPULATIONS

Public Awareness and Appropriate Use of IHC

Although public awareness of technology, such as the Internet, is widespread, many people, including health professionals, do not know which health-related applications are available or which ones are appropriate for their needs. Greater awareness of the appropriate selection and use of IHC applications may lead to widespread use of high-quality products and discourage use of poor-quality ones, thus, maximizing the benefits and minimizing the potential for harm from IHC.

- ***Entities with an interest in health and technology should promote public and professional education about the availability, selection, and optimal use of high-quality IHC applications.*** Potential participants in this activity include government agencies and nonprofit organizations, particularly professional organizations. Consumers should be educated about the potential benefits of IHC, as well as the potential for harm from inappropriate use of applications. The initiative should disseminate information about what is available, what IHC can be expected to do (i.e., as a complement to, rather than as a substitute for, personal health services), how to access IHC applications, and how to recognize high-quality and appropriate applications.

Access to Infrastructure

Both public and private sector stakeholders, particularly government agencies and corporations, will need to collaboratively reduce the gap between the health information "haves" and the "have-nots." For this to happen, a range of activities will be necessary including supporting health information technology access in homes, workplaces, and public places, developing applications for the growing diversity of potential users, and improving literacy in health and technology, especially among underserved populations.

- ***Public-private initiatives to enhance access to IHC among the underserved should be established.*** Potential partners in such an initiative include government agencies, private foundations, and corporations with an interest in technology and health. Such an initiative should include efforts to improve access to the Internet at home and in public places. Both public and private sector funding of this initiative is indicated because of the cost and because both sectors directly benefit from improved access.

Applications for the Underserved

Applications that address rare health conditions or target certain populations (e.g., disabled communities, low-income groups, certain racial/ethnic groups, and non-English speaking populations) are not a focus for commercial developers. Many of these orphan applications are not being produced in the current market environment because developers lack the skills or experience in developing applications for these communities. These products also are not economically viable because the target audiences are too small or because the potential users cannot afford to pay for the application.

- ***Mechanisms and models should be established to fund the development and implementation of orphan applications, including applications for underserved populations.*** Potential partners in this effort include the Federal government, private foundations, and corporations. Applications for underserved populations will need to address a wide array of issues among population groups including sociocultural norms about health, literacy skills, and communication approaches. Funding also will be needed for demonstration projects in specific communities.

Conclusion

There is little doubt that IHC applications will continue to grow and that consumers will increasingly turn to them for health information, communication, support, and transactions. IHC has the potential to dramatically improve the ways in which people prevent disease, maintain their health, and recover from illness. Rapidly evolving technologies may impact health and health care in ways that few of us imagine. However, for IHC to play a pivotal and positive role in creating a healthier society, a range of initiatives is needed and many stakeholders must participate in application development and evaluation. Consumers will need to assess applications before using them and avoid using unevaluated ones, developers will need to implement evaluation methods throughout the development process, health professionals will need to become involved in application development and refer their patients to high-quality products, information intermediaries will need to help consumers select applications and interpret health information, health care purchasers will need to demand evaluated products, and policymakers will need to implement policies that support the development and use of high-quality applications.

An evidence-based approach to the development and diffusion of IHC applications is central to the process of ensuring that IHC applications are of high quality, effective, and accessible to all. National initiatives that focus on strengthening evaluation and quality of IHC, improving knowledge and understanding of IHC, enhancing capacity of stakeholders to develop and use IHC, and improving equal access to IHC, could enable us to reap its many potential benefits to individual and public health.

VIII

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Appendixes

Appendix A

EVALUATION REPORTING TEMPLATE FOR IHC APPLICATIONS

The template is divided into four sections. Section I focuses on identification of the developer(s), the source(s) of funding for the application, the purpose of the application and its intended audience(s), technical requirements, and issues of confidentiality. Assurance of confidentiality will become increasingly important as applications that collect and utilize personal health information, such as those that assess individual risk for sensitive health conditions, proliferate.

Section II focuses on the results of formative and process evaluations, as contributors to application design and development. These items elicit information to help potential users and purchasers judge validity of the content, appropriateness of the application to their specific needs, and whether sufficient testing was done to ensure that the application functions as intended. This section attempts to go beyond the simple disclosure of the descriptive elements (e.g., identity of the developers, sponsorship and purpose of the application) to encourage disclosure of whether and how potential users and other "experts" were involved in application development and how extensively the application was tested prior to release.

Section III focuses on the results of any outcome evaluations performed. The list of outcomes are not exhaustive but includes those most commonly encountered, ranging from user satisfaction to changes in morbidity or mortality, reduced costs, or organizational change. Potential outcomes are broadly defined because individual developers, users, and purchasers may have very different needs and expectations. For example, while one developer or potential purchaser may be interested in an application that improves management of specific chronic disease symptoms, another may be solely interested in improving general patient satisfaction. Classifications of evaluation designs from the US Preventive Services Task Force are included to provide information relevant to the internal validity of the results (i.e., the strength of evidence that the observed results are due to the intervention). Descriptions of samples are also included to provide information relevant to the "generalizability" of results.

Section IV focuses on information about evaluators and funding to provide potential users and purchasers with information about potential biases or conflicts of interest relevant to the evaluation. The template also attempts to increase accountability for IHC applications by encouraging the disclosure of the person(s) responsible for design and content (Section I) and evaluation (Section IV).

Evaluation Reporting Template for IHC Applications, Version 1.0, Science Panel on Interactive Communication and Health

This is an evaluation reporting template for developers and evaluators of interactive health communication (IHC) applications to help them report evaluation results to those who are considering purchasing or using their applications. Because the template is designed to apply to all types of applications and evaluations, some items may not apply to a particular application or evaluation. Complete only those items that apply. This and subsequent versions of the template and other resources on evaluation of IHC are available at: URL:http://www.scipich.org

Comments and suggestions regarding the content, scope, utility, and practicality of this template should be directed to: SciPICH, Office of Disease Prevention and Health Promotion, US Department of Health and Human Services, 200 Independence Ave., SW, Room 738G, Washington, DC 20201 or e-mail comments to: scipich@health.org

I. Description of Application

1. Title of product/application:
2. Type of application (e.g., Web site, CD-ROM/DVD):
3. Name(s) of developer(s):
4. Relevant qualifications of developer(s):
5. Contact(s) for additional information:
6. Funding sources for development of the application (e.g., commercial company, government, foundation/nonprofit organization, individual):
7. Category of application (e.g., clinical decision support, individual behavior change, peer support, risk assessment):
8. Specific goal(s)/objective(s) of the application (What is the application intended to do? List multiple if applicable):
9. Intended target audience(s) for the application (e.g., age group, gender, educational level, types of organizations and settings,

disease groups, cultural/ethnic/population groups):

10. Available in languages other than English? No Yes (specify):
11. Does the application include paid advertisements, content, or links? No Yes
12. Technological/resource requirements of the application (e.g., hardware, Internet, on-site support available):
13. Describe how confidentiality or anonymity of users is protected:
14. Indicate who will potentially be able to get information about users:

II. FORMATIVE AND PROCESS EVALUATION*

1. Indicate the processes and information source(s) used to ensure the validity of the content (e.g., peer-reviewed scientific literature, in-house "experts," recognized outside "experts," consensus panel of independent "experts," updating and review processes and timing):
2. Are the specific original sources of information cited within the application? Yes No
3. Describe the methods of instruction and/or communication used (e.g., drill and practice, modeling, simulations, reading generic online documents, interactive presentations of tailored information, specify methods used):
4. Describe the media formats used (e.g., text, voice/sound, still graphics, animation/video, color):
5. For each applicable evaluation question below indicate (i) the characteristics of the sample(s) used and how they were selected, (ii) the method(s) of assessment (e.g., specific measures used), and (iii) the evaluation results:
6. If text or voice is used, how was the reading level or understandability tested?
7. What is the extent of expected use of the application (e.g., average length and range of time, number of repeat uses)?
8. How long will it take to train a beginning user to use the application proficiently?

9. Describe how the application was Beta tested and debugged (e.g., by what users, in what settings):

III. OUTCOME EVALUATION**

1. For each applicable evaluation question below, indicate (i) the type of evaluation design (I-III),*** (ii) the characteristics of the sample(s) used and how they were selected, (iii) the method(s) of assessment (e.g., specific measures used), and (iv) the evaluation results:
2. How much do users like the application?
3. How helpful/useful do users find the application?
4. Do users increase their knowledge?
5. Do users change their beliefs or attitudes (e.g., self-efficacy, perceived importance, intentions to change behavior, satisfaction)?
6. Do users change their behaviors (e.g., risk factor behaviors, interpersonal interactions, compliance, utilization of resources)?
7. Are there changes in morbidity or mortality (e.g., symptoms, missed days of school/work, physiologic indicators)?
8. Are there effects on costs/resource utilization (e.g., cost-effectiveness analysis)?
9. Do organizations or systems change (e.g., resource utilization, effects on "culture")?

IV. BACKGROUND OF EVALUATORS

1. Names and contact information for evaluator(s):
2. Do any of the evaluators have a financial interest in the sale/dissemination of the application? No Yes (specify):
3. Funding sources for the evaluation(s) of the application (e.g., developer's funds, other commercial company, government, foundation/nonprofit organization):
4. Has the evaluation been published in a peer-reviewed scientific journal? No Yes
5. Is a copy of the evaluation report(s) available for review on request? No Yes (how to obtain):

* **Formative evaluation** is used to assess the nature of the problem and the needs of the target audience with a focus on informing and improving program design before implementation. This is conducted prior to or during early application development, and commonly consists of literature reviews and reviews of existing applications and interviews or focus groups of "experts" or members of the target audience. **Process evaluation** is used to monitor the administrative, organizational, or other operational characteristics of an intervention. This helps developers successfully translate the design into a functional application and is performed during application development. This commonly includes testing the application for functionality and also may be known as alpha and beta testing.

** **Outcome evaluation** is used to examine an intervention's ability to achieve its intended results under ideal conditions (i.e., efficacy) or under real world circumstances (i.e., effectiveness), and also its ability to produce benefits in relation to its costs (i.e., efficiency or cost-effectiveness). This helps developers learn whether the application is successful at achieving its goals and objectives, and is performed after the implementation of the application.

*** **Design types** are grouped according to level of quality of evidence as classified by the US Preventive Services Task Force and the Canadian Task Force on the Periodic Health Exam. (US Preventive Services Task Force. *Guide to Clinical Preventive Services. 2nd Ed.* Washington, DC: US Department of Health and Human Services; 1996.)

I. Randomized controlled trials. Experiments in which potential users are randomly assigned to use the application or to a control group. Randomization promotes comparability between groups. These designs can be (a) doubleblinded: neither the participants nor the evaluators know which participants are in the intervention group or the control group, (b) single-blinded: the participants are not aware which experimental group they are in, or (c) non-blinded: both the participants and the evaluators are aware of who is in the intervention group and who is in the control group. Greater blinding lessens the chance of bias.

II-1. Nonrandomized controlled trials. Experiments comparing users and nonusers (or "controls") but they are not randomly assigned to these groups. For this type of design specify how the participants were recruited, selected, and assigned to the groups and how the groups compare (similarities and differences between users and nonusers) prior to the evaluation.

II-2. Cohort study/observational study. An evaluation of users with no comparison or control group.

II-3. Multiple time series. Observations of participants as they go through periods of use and nonuse of the application.

III. Descriptive studies, case reports, testimonials, “expert” committee opinions.

Original version was published in: Robinson TN, Patrick K, Eng TR, Gustafson D, for the Science Panel on Interactive Communication and Health. An evidence-based approach to interactive health communication: a challenge to medicine in the Information Age. *JAMA.* 1998;280:1264-1269.

Appendix B

DISCLOSURE STATEMENT (LABEL) FOR IHC APPLICATIONS

The following is a template that developers could use to disclose information about their application when there is a need to relay core information quickly to potential users and purchasers. This statement may be especially useful for applications that are marketed directly to users. The statement can be derived from appropriate elements of the "Evaluation Reporting Template" in Appendix A.

Disclosure Statement (Label) for IHC Applications

Name of Application____________________________________

Type of Application (e.g., Web site, CD-ROM/DVD):______________

Developer(s)/Sponsor(s)

- Identity and organizational affiliation of developer/sponsor:
- Contact information for developer/sponsor:
- Source(s) of funding for development:
- Does the application include paid advertisements, content, or links?

Purpose

- Specific purpose of application:
- Target audience for the application:

Content

- List the original source(s) of the content:

Privacy

- How users' confidentiality or anonymity will be protected and who will have access to collected personal data:

Evaluation

- Was the effectiveness or impact of the application evaluated?
- If yes, provide a summary of results (i.e., describe evaluation design/methods, study sample, key positive and negative results, identity and funding of evaluators, and whether published in a peer-reviewed scientific journal):
- How and/or where a report of the full evaluation results can be obtained:

Appendix C

POTENTIAL FUNDING SOURCES FOR IHC DEVELOPMENT AND EVALUATION

The following are major potential resources related to government and private-sector funding for IHC development and evaluation:

Government Sources

Agency for Health Care Policy and Research—Funding Opportunities:
http://www.ahcpr.gov/fund/

Centers for Disease Control and Prevention—Funding Opportunities:
http://www.cdc.gov/od/pgo/funding/funding.htm

Health Resources and Services Administration—Grants and Contracts:
http://158.72.83.3/grants.htm

National Science Foundation—Grants and Awards:
http://www.nsf.gov/home/grants.htm

NIH Office of Extramural Research. Small Business Funding Opportunities:
http://www.nih.gov/grants/funding/sbir.htm

Substance Abuse and Mental Health Services Administration Grant Funding Opportunities:
http://www.samhsa.gov/grant/gfa_kda.htm

Telecommunications and Information Infrastructure Assistance Program (TIIAP), US Department of Commerce:
http://www.ntia.doc.gov/otiahome/tiiap/index.html

Private-Sector Sources

National Venture Capital Association:
http://www.nvca.org/

The Foundation Center:
http://fdncenter.org/

Appendix D

PURCHASER'S EVALUATION CHECKLIST FOR IHC APPLICATIONS

This checklist is intended to help potential purchasers of IHC applications, especially health plans and other health care organizations and large employers, in their decisionmaking process, and to focus on relevant evaluation results reported by developers using the Panel's "Evaluation Reporting Template" in Appendix A. Careful evaluation and a systematic approach to decisionmaking will help you and your organization weigh the pros and cons of a new system, delineate what you expect from the system, and select a product (or decide not to purchase one) that is most compatible with the needs and resources of your organization.

Major questions to consider:

1. Why was the application developed?*

- What clinical or business problem(s) does the application propose to solve (e.g., reduce cost, improve quality, and enhance prevention, satisfaction, and efficiency)?

2. What does the program propose to do?*

- What types of outcomes are expected?
- What are the findings from related literature? How did they guide the developer?
- Can the program be tailored to individual patients?
- How does it link with care delivery (e.g., case management, appointments)?
- What setting is most appropriate for the program (e.g., clinic, home, school, community)?

3. What are the technical requirements of the application?*

- How are the data collected and stored?
- What training do providers need to use the application?
- What personnel infrastructure is needed to implement the program?
- What technical infrastructure is needed?

- How often does the content need to be updated? Who will take responsibility for it?

4. Does the program work as described? **, ***

- What are the limitations of the application given overall content, design, usability, cultural appropriateness, language, and related factors?
- Why is this technology best suited for the product goals?
- How has feasibility testing been done?
- How were the intended outcomes evaluated? What were the results?
- What is the user experience?

In addition, potential purchasers should consider the following questions that are specific to their organization:

5. What are the likely benefits for the specific organization (why should senior management buy-in)?

- Why does the organization need it?
- Where does the application fit in the organization?
- What is the significance of the clinical area and target population for this organization?
- What is the complexity of the clinical problem(s) addressed by the product?
- What is the likely impact on utilization and quality?
- What is the total cost to the organization? What is the overall cost benefit? What is the cost-benefit model for using the system?
- How does the purchaser perceive overall effectiveness?
- What budget would be used (e.g., medical versus marketing)?
- How will the product help with marketing and overall image/market position?
- What are competing organizations doing in this area?

* See “Section I. Description of Application” of the Template (Appendix A)
** See “Section II. Formative and Process Evaluation” of the Template (Appendix A)
*** See “Section III. Outcome Evaluation” of the Template (Appendix A)

Appendix E

CONSUMER'S GUIDE TO EVALUATING IHC APPLICATIONS

This guide is intended to help consumers interpret evaluation results reported by developers using the Panel's "Evaluation Reporting Template" in Appendix A. The standardized reporting of evaluation results should help you decide how well IHC applications meet your own needs and help you interpret evaluation results by using the template structure.

To decide whether an IHC program will help meet your specific needs, you will want to know general information about the application and its intent, how the application was developed, how well it "runs," and whether the application achieves its intended effects. The following are questions a consumer might want answered in the best of circumstances. Unfortunately, some of this information may not be easily accessible for many current IHC applications. The Panel wants to help consumers avoid purchasing or using applications that do not provide the information and support needed to make informed decisions.

1. Description of the Program

- What are the qualifications of the developers? Programs are more likely to be good if developers are "experts" in the content area and have previously developed effective IHC applications.
- Who sponsored or paid for the program? Programs supported by organizations that have something to gain (e.g. tobacco companies who might support a program on smoking) should be suspect.
- What is the IHC application intended to do? What are the specific goals and objectives of the application? Do these match your needs?
- What type of user(s) was the application designed for? Some applications are designed for certain age groups, men or women (or both), certain ethnic or cultural groups, or certain socioeconomic groups. Is the application intended for a specific type of user? Is it appropriate for you?
- How does the application protect your confidentiality or anonymity? Who will be able to get information about the users?

2. Formative and Process Evaluation

These evaluations are normally part of the development and testing of a new program. Developers use formative evaluation to create applications with a better chance of succeeding in their goals and use process evaluation to make sure the application "runs" well. The application could tell you:

- Where the content came from and what was done to ensure that it is valid and current. For example, content may come from the published scientific literature, individual "experts," or from the consensus of several experts. What are the backgrounds of the experts? Who sponsored the development? Are the sources of information specified in the application? Can you trust these sources to be current, reliable, and without bias (objective)? Is the content updated at least frequently enough to make sure it is accurate and up-to-date?
- Whether the content was presented in a way that makes it easy for you to learn. Is it easy to understand? Are the words easy to understand? Graphics, video, and animation can make learning easier, but sometimes they are used just to be fancy. Look to see whether these features are there and whether they actually help you learn. Is the material presented in a way that is tailored to your particular needs or do you have to search hard to find content that helps you?
- How the application was tested for reading level or understandability. Whom was this tested on and how was it performed? Is it likely to be appropriate for you?
- Ease of learning. It might be appropriate to have to spend some time learning how to use an application if you plan to use it over and over. But even then, the program should be easy to learn and use.
- Opportunities for users to suggest improvements to programs.

3. Outcome Evaluation

Outcome evaluations test whether an application does what it is supposed to do. Does it achieve its goals? Some applications try to help you change your behavior (e.g., eat less fat), others try to help you choose between treatment options (e.g., surgery vs. drug therapy), and still others try to provide you with social interaction and support from others. Make sure the goals of the application match your needs. Then, see if there have been outcome evaluations to answer the following questions:

- How much do users like the application?
- How helpful do users rate the application?
- Does the application increase users' knowledge?

- Do users change their beliefs or attitudes in a good way?
- Do users improve their behaviors?
- Do users get healthier and/or do their symptoms improve?
- Do users change their use of health care resources or the costs of their health care?
- Did users experience any bad outcomes?
- Is your privacy protected? Who will use the information you provide, and how will they use it?

The information about the program could also help decide whether to believe the results and whether you are likely to get the same results. You do not need to be an expert in evaluation to decide whether to believe evaluation results. Here are some simple rules to follow.

1. How good is the evaluation design?

The most valid evaluation is a series of “randomized, doubleblind, controlled trials.” *Controlled trials* compare people who use the program to those who do not, to be sure that changes found would not have occurred without the program. *Randomized* means that people in the study were assigned randomly (e.g., by flipping a coin) to either get or not get the program. *Double blinding* means neither subjects nor evaluators know who got the program, so answers to evaluation questions are not influenced by the excitement of being in the test group or disappointment of being in the comparison group. It is difficult to “blind” a computer program evaluation, unless everybody gets a computer, some containing the program and some with general health information. Finally, a single study cannot prove program effectiveness; you need several, or a series of, studies. Although they are not proof, studies can be informative if they are only controlled but not randomized or blinded. And although randomized controlled trials are good for learning whether the program works, they do not tell you why. Many people like “qualitative studies,” where evaluators watch people use the program or interview them or look at computer records of how they used the program. They learn a lot, even though these qualitative studies cannot “prove” a program really helps. Bottom line: avoid “evaluations” based only upon user testimonials or expert endorsements. They are not worth much. If risks of harm are small (including risks to time, money, or health) a less-rigorous evaluation may be appropriate. As risks increase, you need more evaluation. If you will use the program to make important health decisions, you may want one that has been tested in several randomized, controlled evaluations.

2. Is it likely that I will experience the same results?

Some evaluations are done using such unique participants, or in such a different place and time, that the results may not apply to you. For example, men and women or young and old users do not always have the same response to applications. Moreover, evaluations from 10 years ago might not produce the same results if performed today. Evaluations cannot be done for all types of people in all places and at all times. Since many programs have different effects on people, some may be helped more than others. Some may even be harmed. You must decide whether the people used in the evaluation (their age, gender, location, education, living situation) are similar enough to your situation that the results are likely to hold for you. That means it is reasonable to expect that evaluators of a program could tell you what kind of people were subjects in the evaluation, so you can decide if they are enough like you. One way to determine this is to look for personal stories in the program. They not only make learning easier but also indicate the type of people for whom this program was designed.

3. Are the evaluators unbiased?

How much you believe the results of an evaluation could depend upon who performed the evaluation. Users will want to know the answers to the following questions:

- Do any of the evaluators have a financial interest in the sale/dissemination of the application?
- Who funded the evaluation? Many evaluations will be carried out or financed by the developers themselves—people who want the application to succeed. Financial interest and funding by an “interested party” does not invalidate an evaluation. However, because evaluation results can be presented in a way that highlights positive findings and hides negative findings, a user might prefer that evaluations are completed and reported by an independent party. Because that is likely to be rare, users must be educated consumers who are on the lookout for ways in which evaluation results may be “spun” to make them want to use an application.
- Is a copy of the evaluation report(s) available for review on request? If the potential risks are great, you or someone you trust should review the evaluation results.

Appendix F

POTENTIAL ACTIVITIES FOR CLINICIANS IN PROMOTING AN "INFORMATION-FRIENDLY" PRACTICE

- Familiarize yourself with the spectrum and functions of interactive health communication (IHC) technologies. Educate yourself about ways to evaluate their quality and impact, especially health information on the Internet. Attend seminars and meetings in this emerging area. Consult with knowledgeable colleagues.
- Learn how to use Web search engines to locate health information. Start by learning how to use popular search mechanisms, such as healthfinder®[1] (http://www.healthfinder.gov/) and Medline[2] (http://www.nlm.nih.gov/). Consult with medical librarians about search strategies.
- Encourage your patients to be active participants in their health care and share clinical decisions by enlisting them to learn more about their condition. Provide standard written guidance about how to find high-quality and relevant information resources and how to be an informed consumer of IHC. When you give your patient or family members information about a diagnosis, test, or other health issue, write down some keywords clearly on an "information prescription" and suggest how they may be able to find additional information on Web sites and in journals, books, and other resources that you have selected. Invite patients to bring in information that they have found. Survey your patients about how your practice can become more "information-friendly."

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[1] healthfinder® is a federally sponsored gateway consumer health information Web site that provides selected online publications, clearinghouses, databases, links to Web sites, and information about support and self-help groups. Sources include government agencies and nonprofit organizations that produce reliable information for the public.

[2] Medline is now available to clinicians and the general public for free and can be searched through either Internet Grateful Med or PubMed. The National Library of Medicine site also provides access to other important resources for clinicians and the public, such as clinical practice guidelines.

- Develop and implement information technology (including Web site) policies, standards, and practices that promote quality, privacy, and confidentiality. These should address who can access, add to, or modify Web sites; security measures to protect against external tampering; and encryption for e-mail containing medical records and other patient information.
- Create a Web site for your practice that may include office information and links to Web sites that you judge to be appropriate. Encourage patients to communicate with you and your staff by e-mail. Sponsor or host a listserv, Web forum, or newsletter to allow patients to support each other and share useful information resources on a regular basis. Participate in online discussion groups to learn about the needs of patients.
- Provide patient access to the Internet in your office or waiting area, and place terminals in locations that are accessible while maintaining privacy and confidentiality. “Bookmark” high-quality and relevant sites on the Web browser.
- Designate a staff member to serve as the leader and coordinator for information technology issues (much like an information technology specialist or chief information officer in a business or organization). He or she should regularly surf the Web and peruse reviews of IHC applications for information relevant to the clinicians and patients in the practice, such as late-breaking research from news sites and online journals. This person also could identify and monitor major Web sites, listservs, and online support groups that are most relevant to the practice. This person does not have to be a health professional, but should be someone with an interest in technology and some training.
- Advocate for evaluation of IHC applications before you endorse them to your patients. Health care professionals should demand evidence of efficacy and safety, just as they do for other health interventions.

Appendix G

BIBLIOGRAPHY AND GLOSSARY OF IHC TERMS

Bibliography

A list of major peer-reviewed literature related to IHC is available at:

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Glossaries

The following online glossaries provide definitions for IHC- and Internet-related terms and concepts.

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Appendix H

PANEL AND STAFF BIOGRAPHIES

Members

Linda Adler, MPH, MA, develops Web-based applications that enable users to obtain health-related information and social support and to make health care decisions. She is a co-investigator for Kaiser Permanente's Patient-Provider Matching Project, a research effort to determine the impact of decision support in the area of physician selection, funded by the Robert Wood Johnson Foundation. She is also a developer of the discussion group forum for Kaiser Permanente Online. Linda has worked for many years in the areas of computerized decision support, health education, and shared decisionmaking. In addition, she is a co-author of *The 1996 Health Informatics Directory*. She has a masters degree in communication research and a masters degree in public health.

Farrokh Alemi, PhD, is an associate professor of health administration at George Mason University's College of Nursing and Health Science. He received his PhD in industrial engineering (decision analysis) from the University of Wisconsin-Madison. The Health Care Financing Administration, the National Institute of Drug Abuse, the Robert Wood Johnson Foundation, the Cleveland Foundation, and a number of other foundations and private companies have supported his research. Dr. Alemi's research has focussed on the application of computers to improving health of underserved populations. In 1996, the October supplement of *Medical Care* was devoted to his research on computer services to cocaine-using pregnant patients. Dr. Alemi has provided testimony to the US Congress concerning the use of computer services to patients' homes. He has started two software companies, and is currently president of TelePractice, a company focussed on online treatment of substance abuse. Dr. Alemi teaches online about various topics including medical informatics. More information and contact details are available at http://mason.gmu.edu/~falemi/informatics/frcv.htm.

David Ansley* is editor-in-chief of OnHealth.com, a consumer-oriented health news and information Web site published by OnHealth Network Co. of Seattle. During his tenure with the Panel, he was employed by Consumers Union for four years, where he was science editor of *Consumer Reports* magazine and the Web editor of *Consumer Reports Online*. He was also the science and medicine editor of the *San Jose Mercury News* and acting director of a science journalism fellowship program at the Massachusetts Institute of Technology. He has a degree in communication from Stanford University.

Patricia Flatley Brennan, RN, PhD, holds the Moehlman Bascom Professorship, School of Nursing and College of Engineering, University of Wisconsin-Madison. Dr. Brennan received a masters of science in nursing from the University of Pennsylvania and a PhD in industrial engineering from the University of Wisconsin-Madison. She completed seven years of clinical practice in critical care nursing and psychiatric nursing before holding several academic positions. She developed and directed the ComputerLink, an electronic network designed to reduce isolation and improve self-care among home care patients, and is presently overseeing the HeartCare initiative, a Web-based cardiac recovery service. Dr. Brennan is a fellow of the American Academy of Nursing and a fellow of the American College of Medical Informatics. She is a founding associate editor for the *Journal of the American Medical Informatics Association*. Currently president-elect, Dr. Brennan will serve as president of the 4,000 member American Medical Informatics Association.

Molly J. Coye, MD, MPH, is a senior vice president in public policy practice and director of the West Coast Office of the Lewin Group. Previously, she served as executive vice president of strategic development for HealthDesk Corporation, a developer of software for online patient health and disease management. Dr. Coye also served as senior vice president for the Good Samaritan Health System, a nonprofit integrated health care system and the largest provider system in the Santa Clara Valley. She was responsible for the operation of four hospitals, the Visiting Nurse Association, the Good Samaritan Medical Foundation, a managed care delivery system including a multispecialty group practice, and an IPA serving 70,000 HMO members. Additional professional positions held by Dr. Coye include director of the California Department of Health Services, commissioner of health for the State of New Jersey, and head of the Division of Public Health at the Johns Hopkins School of Hygiene and Public Health. Dr. Coye is a member of the Institute of Medicine and the National Academy of Public Administration. She has authored two books on Chinese history and is a Trustee of the China Medical Board.

David H. Gustafson, PhD, MS (Chair), is professor of industrial engineering and preventive medicine at the University of Wisconsin-Madison, where he directs the development and evaluation of CHESS (the Comprehensive Health Enhancement Support System), a computer system to help people cope with breast cancer, AIDS/HIV, heart disease, Alzheimer's disease, alcohol abuse, and sexual assault. He is a recognized expert in how demographic factors influence the use of interactive health communication technologies. Dr. Gustafson also has developed new methods and models to document consumer needs in quality improvement and to measure customer satisfaction, severity of illness, medical underservice, and quality of care. He has served on numerous national committees and task forces related to health, health care quality, and informatics. Dr. Gustafson is the author of four books and 100 papers in professional journals, proceedings, and books and recently received the National Information Infrastructure Award of Merit. He received his MS and PhD from the University of Michigan.

Joseph V. Henderson, MD, **MA, MPhil**, has 15 years experience as a multimedia developer and medical educator. He founded and directed the Center for Interactive Media in Medicine at the Uniformed Services University of the Health Sciences in Bethesda, MD, where he developed ground-breaking multimedia applications that are still considered prime examples of exciting and effective uses of these technologies. For the past decade he has directed the Interactive Media Laboratory (IML) at Dartmouth Medical School, where he has been developing interactive multimedia programs for health professionals and patients. The latter group includes four of the Shared Decision Programs distributed by the Foundation for Informed Medical Decision Making. Dr. Henderson has consulted extensively for industry in the areas of technology-based training, medical informatics, multimedia production, and networked multimedia services. Recently, he has been assisting the development of a global distance learning system for the US Army by developing advanced applications and tools better to anticipate the arrival of ubiquitous, broadband networks. The IML and the Centers for Disease Control and Prevention have just begun a project to develop a next-generation distance learning system for public health.

Holly B. Jimison, PhD, is assistant professor of medical informatics and assistant professor of public health and preventive medicine at Oregon Health Sciences University. She also serves as director of the Informed Patient Decisions Group, conducting research on methods to enable patients to be active and informed participants in their health care decisions. Current research and consulting projects include work on computer decision models to tailor consumer health information; communication methods using Web, phone, and paging technologies for patients in the home; measuring patient preferences for health outcomes; and the evaluation of self-care and shared decisionmaking interventions. Dr. Jimison received her doctorate in medical information sciences at Stanford University, with dissertation work on using computer decision models to tailor patient education materials to individuals.

Nancy Metcalf** specializes in health, medicine, and environmental topics as associate editor of *Consumer Reports,* published by Consumers Union. A graduate of Wellesley College and the Columbia University Graduate School of Journalism, she has been a science writer and editor for the past 20 years. She has won a Front Page Award, a Science-in-Society Journalism Award from the Council for the Advancement of Science Writing, and has been a finalist for the National Magazine Award.

Albert G. Mulley, Jr., MD, MPP, is associate professor of medicine and associate professor of health policy at Harvard Medical School, and chief of the General Medicine Division and director of the Medical Practices Evaluation Center at Massachusetts General Hospital. After receiving degrees in medicine and public policy from Harvard, he completed his residency training in internal medicine at Massachusetts General Hospital. He is author and editor of the leading text, *Primary Care Medicine*, as well as many articles in the medical and health services research literature. Dr. Mulley has conducted pioneering work in the application of clinical epidemiology and decision theory to the evaluation of medical intensive care, primary care including prevention and screening, and other health care services. He served on the Clinical Practice and Clinical Efficacy Assessment Committees of the American College of Physicians and on a number of committees of the Institute of Medicine addressing issues in clinical research and clinical quality improvement. Dr. Mulley has been a member of many professional organizations, including the Institute of Medicine Committee for Quality Review and Assurance in Medicine of the National Academy of Sciences and the Health Services Research Study Section of the National Center for Health Services Research. He has been recognized as a Henry J. Kaiser Family Foundation Faculty Scholar in General Internal Medicine.

John W. Noell, PhD, is a senior research scientist at Oregon Research Institute and vice-president and chief technologist for the Oregon Center for Applied Science. He has been developing award-winning interactive multimedia programs in biology and health for more than 25 years. Emphasizing theory-based approaches to behavior change, Dr. Noell has developed numerous public health-oriented programs with extensive applications of tailoring and message framing. Programs he has developed include adolescent pregnancy prevention, smoking cessation, diet change, date-rape prevention, diabetes management, and others. Dr. Noell designs programs for use in various environments (e.g., clinics, worksites, schools, and homes) using kiosks, LAN-based applications, and the Internet. His current work involves the design and analysis of health communications for interactive applications in behavior change.

Kevin Patrick, MD, MS, is director of the Student Health Center at San Diego State University and adjunct professor of public health at San Diego State University. He is editor-in-chief of the *American Journal of Preventive Medicine*, past president of the Association of Teachers of Preventive Medicine, and served on the Secretary's Council for Health Promotion and Disease Prevention of the US Department of Health and Human Services (HHS). In addition, he was a senior advisor in communication technology policy at HHS, where he co-chaired the Information Infrastructure Task Force's Sub-Committee on Consumer Health Information and convened the Science Panel on Interactive Communication and Health. Dr. Patrick also served as an advisor to both the NIST Advanced Technology Program and the NTIA Telecommunications and Information Infrastructure Assistance Program. He was a primary investigator or co-investigator in more than $12 million in public and private research and training grants and has authored or co-authored more than 80 scientific articles, book chapters, commentaries, and abstracts on a broad range of topics, including school and student health, public health, infectious diseases, behavioral health counseling, information and communication technology, and consumer health information. Dr. Patrick is board certified in both preventive medicine and family practice.

Thomas C. Reeves, PhD, is a professor of instructional technology at the University of Georgia where he teaches program evaluation, multimedia design, and research methods. Since receiving his PhD at Syracuse University in 1979, he has developed and evaluated numerous interactive multimedia programs for both education and training. In addition to giving more than 100 presentations and workshops in the United States, he has been an invited speaker in many countries including Australia, Brazil, Bulgaria, Canada, China, Finland, Malaysia, Peru, Russia, South Africa, Sweden, Switzerland, and Taiwan. He is a past president of the Association for the Development of Computer-based Instructional Systems (ADCIS) and a former Fulbright Lecturer. In 1995, Dr. Reeves was selected as one of the "Top 100" people in multimedia by *Multimedia Producer* magazine, and since 1997, he has been the editor of the *Journal of Interactive Learning Research*. His research interests include evaluation of instructional technology for education and training, socially responsible research goals and methods in education, mental models and interactive multimedia user interface issues, electronic performance support systems (EPSS), and applications of instructional technology in developing countries.

Thomas N. Robinson, MD, MPH, is an assistant professor of pediatrics and of medicine at Stanford University School of Medicine and the co-director of youth studies at the Stanford Center for Research in Disease Prevention. Dr. Robinson received his BS and MD degrees from Stanford University and his MPH degree in maternal and child health from the University of California at Berkeley. After internship and residency training in pediatrics at Children's Hospital in Boston and Harvard Medical School, he returned to Stanford as a Robert Wood Johnson Foundation Clinical Scholar. He joined the faculty at Stanford in 1993 and was appointed assistant professor in 1996. Dr. Robinson performs school-, family-, and community-based prevention research, focusing on reducing risk factors for cardiovascular disease and cancer, childhood obesity prevention and treatment, tobacco and alcohol use prevention, the effects of television viewing on health-related behaviors, and the use of interactive communication technologies to promote health behavior change. Dr. Robinson is board certified in pediatrics, is a fellow of the American Academy of Pediatrics, and practices general pediatrics at Lucile Salter Packard Children's Hospital at Stanford.

Victor J. Strecher, PhD, MPH, is a behavioral scientist whose work has focused on developing and testing strategies for health behavior change in medical care, community, and occupational settings; studying methods for improving the quality of tailored health communications; researching the determinants of health decisionmaking behavior; and employing experimental and survey research methods in conducting evaluative analyses. Dr. Strecher is a professor and associate director at the University of Michigan's Comprehensive Cancer Center. At this center, Dr. Strecher has created the Health Media Research Laboratory—a group of behavioral and medical researchers, computer programmers, instructional designers, and creative artists organized to develop innovative health education interventions using advanced communications technologies.

* Served until April 1998
** Served beginning April 1998

Staff

Thomas R. Eng, VMD, MPH, is the study director for the Science Panel on Interactive Communication and Health. His areas of interest include the application of communication and information technology in health communication, health care, public health, and epidemiological research. He has a special interest in the use of interactive media to improve the health of underserved populations. Most recently, he was a study director at the Institute of Medicine, where he directed the report, *The Hidden Epidemic: Confronting Sexually Transmitted Diseases*. Previous positions in his public health career include: an American Association for the Advancement of Science Congressional Fellow in the US Senate, Peace Corps' epidemiologist, a preventive medicine resident and Epidemic Intelligence Service Officer with the Centers for Disease Control and Prevention, and an epidemiologist in two State health departments. He has received several awards from the US Public Health Service and other national health organizations. Author or co-author of more than 85 peer-reviewed articles, book chapters, and abstracts on a wide range of health and technology issues, he is also an associate editor of the *Journal of Health Communication: International Perspectives*.

Anne Restino, MA, is health communications manager for the National Health Information Center, where she assists in the development and management of Web-based health communication projects and serves as a senior marketing and outreach specialist and liaison to the Office of Disease Prevention and Health Promotion. She received her masters degree in health communication from the Emerson College-Tufts University School of Medicine joint program. Her graduate work investigated the usefulness of the Web as a health communication tool and included the development, evaluation, and management of the Emerson-Tuft's Health Communication Resources Web site. Ms. Restino has served as project manager for several academic Web sites and has written and spoken on health communication applications for the Web. Previously, she worked in the sales and marketing operations at various consumer product, service, and information organizations.

Paul Kim is a research assistant in the Office of Disease Prevention and Health Promotion. In addition to supporting the Panel, he coordinates the Public Health Functions Project, a collaboration of the US Public Health Service agencies and numerous national public health associations that is convened to strengthen the public health infrastructure. He is a graduate of Stanford University with a degree in biological sciences.

Mary Jo Deering, PhD, is acting deputy director of the Office of Disease Prevention and Health Promotion (ODPHP) and director of its Health Communication and Telehealth Team. She created the Science Panel on Interactive Communication and Health and now oversees its work. She chairs the Work Group for the Health Communication focus area for Healthy People 2010 and serves on the core team within ODPHP that is coordinating the development of Healthy People 2010. She is the lead staff for the National Committee on Vital and Health Statistics' Work Group on a National Health Information Infrastructure. She chairs the steering committees for healthfinder® (www.healthfinder.gov), the official Federal gateway to consumer health information, and for Partnerships for Networked Consumer Health Information, which presents national conferences and the innovative Technology Games. Dr. Deering served on the Federal Communication Commission's Advisory Committee on Telecommunication and Health. She is a member of the editorial board of the *Journal of Health Communication: International Perspectives*, and has authored and co-authored book chapters and articles on health communication and new media.

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